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MULTI-LEVEL BARRIERS TO ART ADHERENCE AMONG HIV- INFECTED WOMEN IN RURAL ESWATINI: A MIXED METHODS APPROACH

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MULTI-LEVEL BARRIERS TO ART ADHERENCE AMONG
HIV-INFECTED WOMEN IN RURAL ESWATINI: A MIXED METHODS APPROACH

A Dissertation Presented

By

NOZIPHO BECKER

Submitted to the Graduate School of the
University of Massachusetts Amherst in partial fulfillment
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

September 2019

School of Public Health and Health Sciences
Department of Nutrition

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DEDICATION

To my beloved family and all women denied an education.

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I consider myself the luckiest woman in the world to have such lovely and caring people standing beside me with unconditional love and support. Thank you all.

ABSTRACT

MULTI-LEVEL BARRIERS TO ART ADHERENCE AMONG HIV-INFECTED WOMEN IN RURAL ESWATINI: A MIXED METHODS APPROACH

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Eswatini has the highest global prevalence of HIV despite universal access to free treatment. Lack of compliance continues to be a significant challenge for HIV care and management programs throughout the country. Studies investigating barriers to antiretroviral therapy (ART) adherence, particularly in women, who are the most vulnerable to HIV infections, are limited. The disproportionate impact of HIV on women can be attributed to multiple risk factors at the individual, household, and community/structural levels. Women living in rural settings are particularly at risk as a result of socio-cultural and environmental vulnerabilities such as oppressive traditional practices, intimate partner violence, and limited access to financial resources.

We employed a mixed methods exploratory sequential design to investigate barriers associated with ART adherence among HIV-infected women living in rural Eswatini. The qualitative phase of the study included four focus group discussions (FGDs n=41) with HIV-infected rural women, and in-depth interviews of healthcare workers (n=8). Data analysis used open and axial coding techniques, with interpretation following the social ecological model. The quantitative phase involved in-person survey interviews of HIV-infected women (n=166) and logistic regression models were used to examine the extent to which critical barriers affected ART adherence.

Intrapersonal barriers to ART adherence include: hunger, side effects of ART, personal stress, stigma, and forgetfulness. Lack of food, lack of disclosure of HIV status, and limited and financial resources were identified as critical barriers at the household level. Community/ institutional barriers included: lack of privacy, travel time, transportation costs, excessive alcohol use, maltreatment, gossip, and long waits at clinics. Of twenty barriers identified from the qualitative phase, nine (hunger, hunger-related medication side effects, feelings of stress, forgetfulness, mode of transport, age, gossip, maltreatment by clinic staff, and community support) were significantly associated with ART adherence.

Numerous factors across multiple levels interact and influence ART adherence. Collectively, our findings pinpoint priority areas to target for development, testing, and evaluation of future interventions aimed at increasing HIV medication adherence among one of the most vulnerable segments of Eswatini's population, HIV-infected women in rural communities.

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CHAPTER 1

INTRODUCTION

Human Immunodeficiency Virus (HIV) is a significant health burden faced by an estimated 36.9 million people globally(1). Despite substantial progress in the fight against HIV in many regions of the world, Sub-Saharan Africa remains the only global area still facing rates of HIV at epidemic levels. Of the world's population infected with HIV, 69% reside in Sub-Saharan Africa. Furthermore, women in this region remain the most severely affected by the epidemic, accounting for 71% of the people living with HIV worldwide(1). While the majority of these women (64%) are receiving HIV antiretroviral therapy, challenges with adherence continue to be a significant problem encountered by this population group(2).

Eswatini, located in southern Africa, has the highest HIV prevalence in the world (27.2%), with the rate being significantly higher among women (32.5%) than men (20.5%)(3). Currently, an estimated 78% of infected adults in Eswatini are receiving highly active antiretroviral therapy (ART), though data on adherence to ART is very limited(3). Treatments for HIV can improve immune functionality and decrease morbidity and mortality, offering hope that HIV/AIDS can be more effectively managed. Unfortunately, *lapses in ART adherence may render these complex treatment regimens ineffective*(4,5). Currently, Eswatini is challenged with an increase in the number of individuals that are *defaulting on treatment over time*, in spite of government efforts to provide free HIV medications, as well as increased provision for HIV treatment and care at health facilities throughout the country(6).

The consequences of the HIV/AIDS epidemic in Eswatini have threatened the stability of families and communities, thereby adding further stress to an already weakening social and economic infrastructure that is burdened with serious challenges(7). Swazis are also heavily influenced by strong

cultural and traditional values, and these values in turn influence behaviors that impact HIV care and management.

Many families in Eswatini suffer from limited access to resources including food and clean water. Approximately 69% of the Swazi population live below the poverty line, among these, 80% reside in rural areas(8). Furthermore, current estimates indicate that 71% of Eswatini households are food insecure, with over one hundred thousand women receiving ART treatment(9,10). A growing body of evidence indicates that food insecurity increases the risk of HIV transmission, ART nonadherence, and may lead to negative clinical outcomes (such as increased HIV replication, heightened disease progression, reduced viral load suppression, and increased morbidity) among people living with HIV/AIDS(11–15).

Improving ART adherence and reducing morbidity of women living with HIV requires addressing not only individual-level influences on health, but examining these factors within the environmental context in which women live. While previous studies have elucidated factors that facilitate or hinder optimal health among HIV-infected individuals, no known studies have specifically focused on understanding the influence of these factors on ART adherence among women, a particularly vulnerable population group given their disproportionately high infection rates. This poses significant public health challenges because until there is increased knowledge generated on the individual, social, and structural barriers to ART adherence in a country with such a high prevalence of HIV, coupled with high rates of poverty, programs will lack the evidence necessary to effectively target treatment support programs aimed at improving HIV-infected women's (particularly rural women living in poverty) adherence to ART treatment. It is therefore critical to identify factors associated with ART adherence in order to provide scientific data that will help reveal the challenges to treatment, especially for resource-constrained rural women living with HIV.

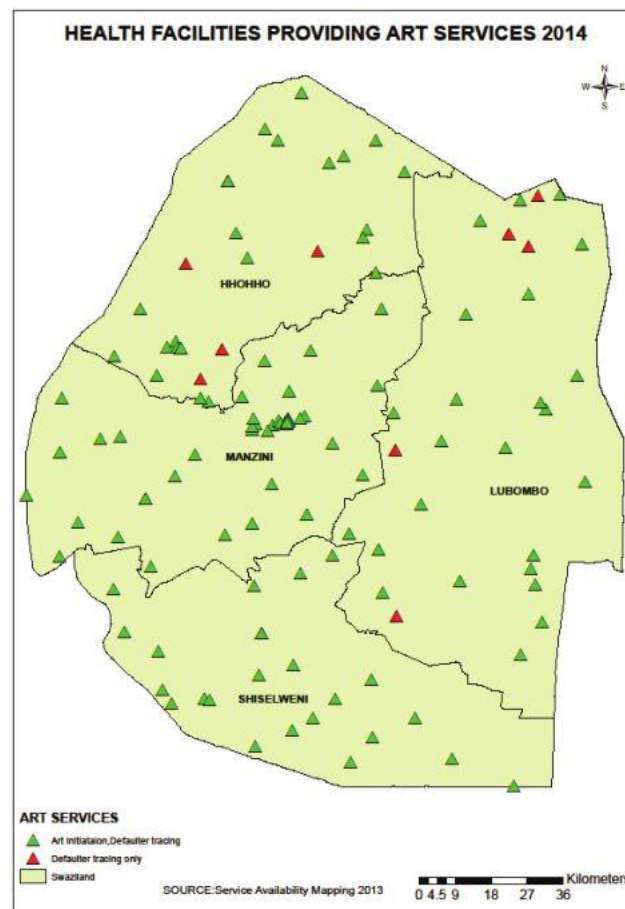
CHAPTER 2

LITERATURE REVIEW

2.1 HIV/AIDS Overview in Eswatini

Currently, ART medications are available for free throughout Eswatini through government clinics and hospitals, and provided for free to all people living with HIV in the country. As of 2013, a majority of health facilities (80.5%) providing ART were public hospitals and clinics (see Figure 1 below). Private hospitals and clinics also provide free ART medications supplied by the government of Eswatini(6).

Figure 1: Distribution of Health Facilities Providing ART Services



2.1.1 HIV Treatment and Management in Eswatini

Eswatini provides HIV testing and counseling (HTC) at all health facilities across the country. There are currently two types of HTC services available: 1) client initiated HIV testing and counseling, and 2) provider initiated HIV testing and counseling. Both HTC services are voluntary and are provided to all citizens free of cost regardless of HIV status. Individuals diagnosed with HIV are started on ART (HIV medication) immediately and are instructed to return to the clinic pharmacy each month to collect medication. Clinical visits occur at weeks 2, 4, 8, and 12, then every 3 months, following diagnosis. Weight is recorded at every visit. Assessment of CD4 cell count is performed initially at three months and six months after initiating ART, and then every six months thereafter. Viral load is measured at six months after ART commencement to confirm virological response to ART. After two consecutive suppressed viral load results six months apart, viral load monitoring is conducted annually. Clinical and laboratory data are entered into an electronic patient tracking system, which also tracks scheduled and attended clinical and pharmacy appointments. Adherence counseling is provided before ART initiation and continuously during care at each subsequent follow-up visit(16,17).

ART has contributed significantly to increased survival and improved health outcomes for people living with HIV. Therefore, retention of patients on ART is a very important part of therapy to improve the quality of life for people living with HIV and to reduce the spread of the disease. Currently, the percentage of patients remaining on treatment after ART initiation decreases over time, i.e. as duration on ART increases, ART adherence decreases, Table 1 (18). This is a concern to ART programs as it suggests that patients are being lost to follow-up, and consequently not adhering to medication.

Table 1: Patients' retention rates at 6, 12, 24, 36, 48, and 60 months after ART initiation

Cohort	6 months		12 months		24 months		36 months		48 months		60 months	
	<15 yrs	15+ yrs	<15 yrs	15+ yrs	<15 yrs	15+ yrs	<15 yrs	15+ yrs	<15 yrs	15+ yrs	<15 yrs	15+ yrs
2008	88%	85%	82%	78%	75%	71%	68%	65%	62%	59%	57%	53%
2009	87%	85%	81%	78%	74%	71%	68%	64%	63%	58%	77%	69%
2010	87%	86%	80%	80%	73%	71%	65%	62%	80%	74%	76%	74%
2011	89%	88%	82%	80%	69%	69%	83%	78%	78%	78%		
2012	84%	87%	76%	77%	87%	82%	84%	83%				
2013	85%	86%	91%	88%	87%	87%						
2014	97%	96%	93%	92%								
2015	98%	97%										

Declining retention rates and nonadherence to ART pose significant challenges to HIV treatment and management, particularly for women in their child bearing years since it can negatively impact the prevention of mother-to-child transmission of the disease. Near perfect adherence is required for HIV medications to effectively decrease viral load and increase CD4 T-lymphocytes among people with HIV(4,5). A more comprehensive understanding of the barriers to ART adherence within specific environmental settings, particularly in resource-poor areas in Eswatini, is clearly warranted.

2.1.2 Eswatini and the Burden of HIV

HIV/AIDS is a significant health challenge faced by an estimated 36.9 million people globally. A substantial portion of those people live in sub Saharan Africa, accounting for 71% of the infected population(1). Current evidence suggests prevalence rates ranging from 12.5% to 27.2 % among male and female adults in southern Africa, with Eswatini representing the highest level at 27.2%. Adult HIV incidence in Eswatini is estimated at 1.36%, and is nearly twice as high among women compared to men(3). The prevalence among pregnant women attending antenatal care has increased astronomically from 3.9% in 1992 to 38% in 2013(6).

Since the first case of AIDS was reported in Eswatini in 1986, the virus has spread at an alarming rate. In 2016, an estimated 231,609 people were living with HIV, and approximately 180,248 were receiving antiretroviral treatment. It is estimated that 8,800 people were newly infected in 2016, and among these, 53% were women. HIV/AIDS has been devastating to Eswatini. Orphans and vulnerable

children account for an estimated 15 percent of the total population, and in 2016 approximately 3900 people died from AIDS related illnesses. The impact of the epidemic has been so severe that life expectancy in the country, dropped from 60 years in the 1990s to 49 years in 2013(9,19).

The health care sector in Eswatini has been burdened with an increased prevalence of illnesses associated with AIDS. The admission of AIDS patients to health care facilities has steadily grown throughout the country. Intervention strategies have been adopted by the Swazi government and private organizations to help combat the spread of the pandemic and its associated consequences. Unfortunately, insufficient progress regarding the trajectory of HIV prevalence has been observed thus far. Over the last decade the Swazi government has invested substantial financial and structural resources towards combating HIV, mainly by providing universal free treatment and medication to all of the HIV positive population. In 2009, the Swazi government enacted a National Strategic Framework to guide the implementation of interventions designed to prevent the spread of HIV, decrease vulnerability of individuals and communities to HIV, improve care for those living with HIV, and reduce the adverse socioeconomic effects of the pandemic(20).

The consequences of the pandemic have been felt beyond the health sector and extend to all developmental and social spheres. HIV /AIDS is reversing the socioeconomic gains the country has achieved since independence, by compromising investments in health care, education, agriculture, and human capital. The epidemic is adding further stress to a weakening social infrastructure that is burdened with serious challenges, including increasing unemployment (28%), a rising poverty level estimated at 69%, breakdown of family structure, increased burden on the extended family, gender inequality, and a fiscal crisis generated by a significant reduction in government revenues(7,21). Additionally, resources generated for socioeconomic development have decreased, contributing to deepening poverty. As more people succumb to the pandemic, a vicious cycle is created. Reduction of family incomes due to morbidity, and increased expenditures on health care and funerals, cause a

decline in personal savings and investments(7,22). For unemployed women this is particularly challenging, the deaths of spouses/partners often leave them without any source of income to provide for themselves and their families.

2.2 Women and HIV/AIDS

2.2.1 Women and HIV in Eswatini

Women are disproportionately affected by HIV/AIDS in Eswatini, with approximately 32.5% of women infected compared to just 20.5% of men. HIV transmission occurs mainly through heterosexual intercourse, with women accounting for approximately 53% of all new infections (9). The disproportionate impact of the pandemic on women may be attributed to multiple risk factors including biological, social, behavioral, and socioeconomic vulnerabilities(23).

2.2.2 Women's Anatomy and HIV Infection

Biologically, women are more susceptible to HIV infection than men with regards to heterosexual contact. The physical composition of the female genitalia increases the risk for women to contract sexually transmitted diseases, including HIV. The larger mucosal surface area of the vaginal tract exposes women to pathogens from infected blood or semen. After sexual intercourse, semen can persist in the female genital tract for up to five days which increases the chance of HIV transmission. During a woman's menstrual cycle (approximately seven to ten days after ovulation) the female genitalia is particularly vulnerable to pathogens as the tissues of vaginal tract are more fragile and prone to tearing(23). In addition, vaginal injuries may occur during intercourse, which can increase a woman's risk of acquiring HIV.

2.2.3 Cultural Traditions and HIV Infection

Many Swazi people greatly value their cultural tradition and in turn, these cultural views influence attitudes and behaviors related to HIV/AIDS. Often, cultural norms can place women at greater risk of HIV infection due to social disempowerment, and the traditional inequalities inherent in decision-

making that relates to sexual practices(24,25). Polygamous marriages and having multiple sex partners are common practices among men in Eswatini. Also, Swazi traditions tend to perpetuate subordination, portraying women as men's property. Women are expected to get married whether they want to or not. It is considered socially unacceptable to remain unmarried. In order to bring wealth (dowry or bride's price) to a woman's father or male relatives, those who have difficulties finding husbands are often coerced into marrying "wealthy" men (men with many cows, an esteemed component of the dowry). These wealthy men are also commonly engaged in polygamous marriages. This practice of arranged marriages is especially common among rural households. Uneducated women of low socioeconomic status are particularly vulnerable as they often feel obligated to accept these relationships. Multiple concurrent sexual relationships have been identified as a key driving force of increased HIV infection among women(25,26). The literature also indicates that women, especially the most vulnerable, are typically not empowered to insist on condom use with their husbands or sexual partners, and unsafe sexual intercourse increases the risk for HIV infection (25).

2.2.4 Gender-based Violence and HIV/AIDS

Gender based violence (including sexual abuse) remains a significant challenge for Eswatini and its response to HIV and AIDS. Violence against women is a key factor in the number of women living with HIV/AIDS, with men and boys being the main perpetrators of sexual violence(27). Gender based violence limits the ability of women to negotiate for safer sexual practices, and often interferes with adhering to treatment thus increasing the risk for worsening HIV progression(23,24). Swazi women are generally marginalized, especially those living in rural areas, making them susceptible to abuse, rape and HIV infections. In cases where male partners are in denial of a HIV diagnosis, they may act violently and force their girlfriends/wives to stop seeking HIV treatment and taking their HIV medication(25,27). Considering most rural women are treated as possessions of men, most men expect or demand "sexual" rights. Among married women, husbands often demand sex as a conjugal right and are more likely to

use violence toward women if their sexual advances are refused(25,27). Women suggesting condom use can incite a similar reaction. In a study conducted by UNICEF in 2007, 33.3% of women aged 18-24 years were reported to have had experienced sexual violence by men, with 5% having been forced to have sex before the age of 18(27). Sexual violence and coercion increase the risk of contracting HIV as a direct result of physical trauma, injuries, and bleeding that may occur during intercourse.

2.2.5 Socioeconomic Vulnerabilities

Poverty is one of the primary factors behind the high rates of HIV transmission among women in Eswatini(23,25,28). Poor and uneducated women often resort to transactional sex to financially support themselves. High unemployment and poverty also contributes to a greater incidence of inter-generational sexual relationships. Many young women have sexual relationships with older men who give them money or gifts.

When husbands die from AIDS, often the man's family members blame the wife for being promiscuous and infecting their husbands with HIV. The husbands' family may shun the wife and take all of her assets, as well as evict her from the household. For women living with HIV this is particularly challenging, as they are often stigmatized as immoral and ostracized from their families simply due to being diagnosed with HIV/AIDS(23,29). These societal practices increase the likelihood of women engaging in transactional sex, as they are left with no assets or financial resources to support themselves and their children.

Swazi values and norms uphold men's privileges and have tended to constrain women's autonomy. Culturally, men are regarded as the decision-maker and head of the household. They are expected to go to work, and have control over family resources and finances. Women are expected to stay at home, raise children, do household chores, and are often forbidden from gaining employment or engaging in income generating activities. When women are allowed to work, they are often forced to give most of their income to their husbands or sexual partners(25).

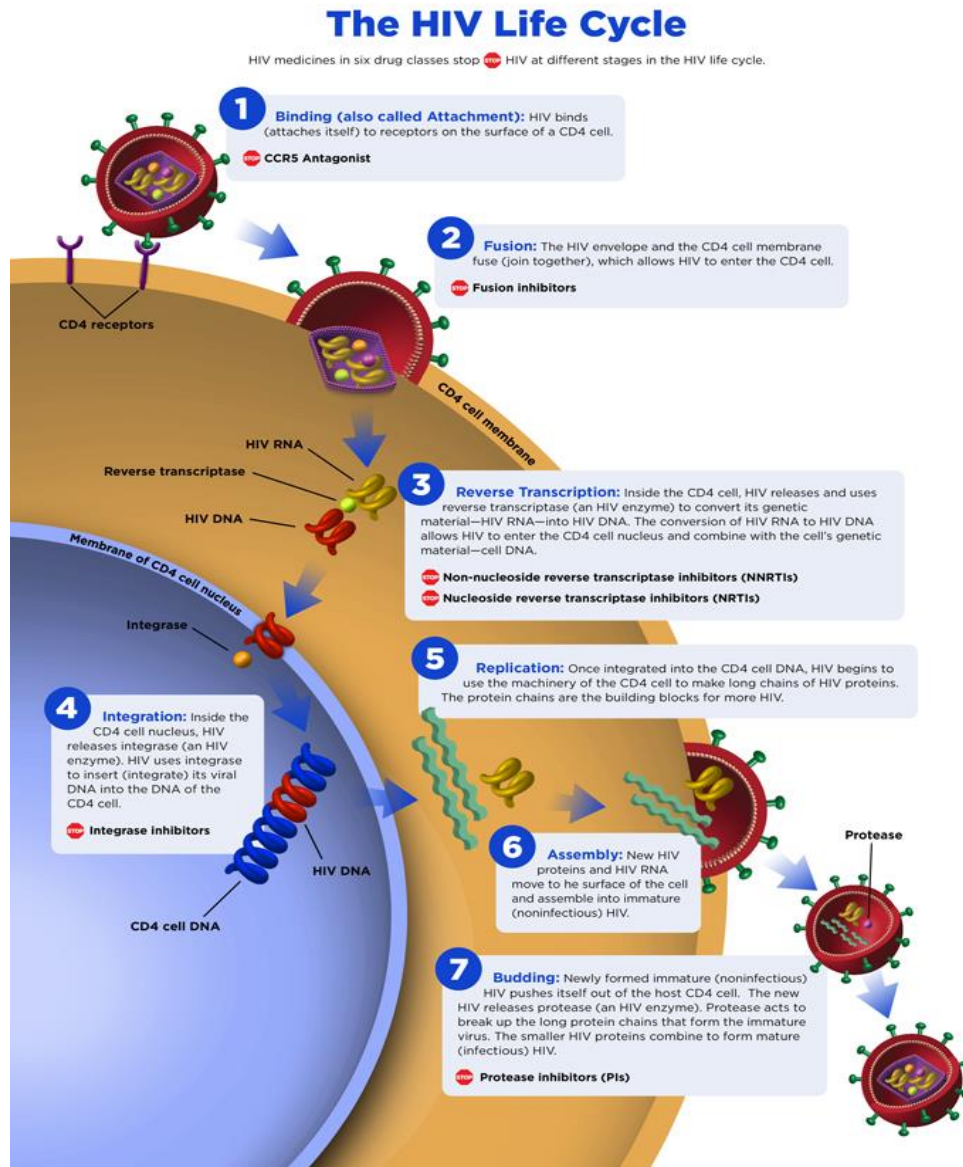
Culturally, when men get married, they are allocated part of their inheritance such as land, money, and livestock, while women are married off without any inheritance. These practices lead to women being financially dependent on men and at increased risk of physical and emotional abuse. Poverty and gender disparities exacerbate HIV transmission by reducing a woman's control regarding issues of safe sex negotiation and sexual rights(24,25), which in turn may influence a HIV-infected woman's care and management practices.

2.3 HIV Infection and Antiretroviral Therapy (ART/ARV)

2.3.1 HIV Life Cycle

HIV attacks cells of the immune system, known as the T-lymphocytes or CD4 cells. During infection, HIV attaches itself to the receptors of a CD4 cell and migrates inside. Once in the cell, the virus replicates and in the process, kills the host CD4 cell, thus resulting in a weakening of the immune system. This process, known as the HIV life cycle, is detailed in Figure 2(30). The progression of this disease can take many years, during which individuals may or may not experience symptoms (Figure 1). To protect the immune system, antiretroviral treatments employ various strategies to block HIV reproduction at different stages of the cycle. This reduces HIV replication in the body and prevents the virus from advancing to AIDS. This adds further stress to the already weakened immune system. During this phase, the immune system becomes too weak to fight pathogens, leaving individuals susceptible to numerous opportunistic infections and cancers, and may result in death.

Figure 2: The HIV Lifecycle



Source: National Institute of Health (AIDSinfo)

2.3.2 HIV Treatment

HIV treatment involves taking medicines (ART/ARVs) that slow the progression of the virus and suppress the virus in the body. If untreated, most people infected with HIV eventually develop AIDS over time and may die without treatment. People on ART are prescribed specific treatment regimens

depending on the stage of HIV infection and how well they tolerate the medication. Often, patients take a combination of medications from at least two different HIV drug classes every day (16). Adherence to prescribed medications is a significant component of effective clinical HIV treatment and care. Optimal adherence to ART is crucial for sustained HIV suppression, improved CD4 cell counts (a measure of a healthier and stronger immune status), decreased risk of HIV transmission, and improved overall health(31,32). Poor adherence to HIV treatment is associated with reduced efficiency of viral suppression and increased risk of opportunistic infections, which may lead to progression to full blown AIDS and mortality (33,34). Effective use of antiretroviral treatment requires more than just taking medication. Patients must be routinely monitored and medication must be taken consistently to ensure optimal viral suppression. Despite substantial progress toward making HIV medication available and affordable for those with HIV, adherence to ART regimen has posed a significant challenge to the treatment of HIV-infected individuals.

2.4 Composition of the Swazi Household and the Role of Women

Most Swazis in rural areas reside in a homestead, comprised of a group of households within a settlement. Within a homestead are a number of households which typically consist of a family (a husband with his wife/wives and their children) whose members share chores, agricultural tasks, and eat from one kitchen. Most rural Swazi households have access to land and primarily depend on subsistence farming for food. The heads of the households (most often males) regulate resource use (such as distribution of farming plots within the family land), and make major decisions regarding both food production (types of crops grown) and economic expenditures. Women often stay at home and manage household chores such as cleaning, cooking, collecting water and firewood, ploughing the fields, and childcare. In addition, with permission from their husbands, poor women often work local seasonal jobs in order to supplement the family income.

2.4.1 Factors Associated with ART Adherence

Epidemiological studies have reported high levels of nonadherence to ART in Sub-Saharan Africa, with rates ranging from 13% to 59% among countries in this region(35–40). A study conducted on HIV-infected pregnant women in Eswatini reported ART nonadherence to be 50%(41). Studies indicate that HIV medication adherence is a complex dynamic behavior influenced by multiple risk factors operating at different levels, from the individual to household and community levels. At the individual level, ART adherence is associated with age, gender, hunger, length of time taking ART, smoking status, alcohol use, depression, income, perceived stigma, and educational level (11,38,40,41). At the household level, ART adherence is associated with household food insecurity, household socioeconomic status, disclosure, family support, and family size(11,42,43). At the community/institutional level, ART adherence is associated with area of residence, proximity to a clinic or health facility, transportation to a health facility, insufficient health care, and maltreatment at health facilities(43–45).

In a recent cross-sectional study, Gary et al. (2015) examined and described factors influencing ART adherence among 30 HIV positive pregnant women in Mbabane, Eswatini(41). Determinants of ART adherence were assessed through interviews during clinic visits. The primary outcome, ART adherence, was assessed using a Patient Medication Adherence Questionnaire. Findings revealed that a better sense of health (80%), familiarity with therapy (90%), and a good patient-healthcare provider relationship (90%) all promoted adherence to ART. Forgetting to take medication, lack of disclosure to family members, limited social support, and self-perceived stigma all contributed to poor adherence³³. While the study provided compelling information on the influences of HIV medication adherence among expectant mothers, generalizability of these findings is limited, as ART adherence was not clearly defined. Another notable limitation was that, since regression models were not included in the analysis, the strength of the association of factors influencing ART adherence could not be ascertained. Furthermore, findings of this study may not be applicable to all women in Eswatini (particularly those in

rural areas), considering that the study population was exclusively pregnant women who attended antenatal care in an urban setting.

In a recent case-control study, Dewing et al. (2015) investigated structural and individual level barriers to ART adherence among 300 adherent and non-adherent HIV positive individuals in Cape Town, South Africa(46). Barriers to ART adherence were assessed using four measurement tools including: a Structural Barrier to Medication-taking Scale, a Substance Abuse and Mental Illness Screener, a Structural Barriers to Clinic Attendance Scale, and a Life Windows Information-Motivation-Behavioral Skills ART Adherence Questionnaire. Participants responded to items using a 5-point Likert scale. ART adherence was measured from medical records using the pill count method. ART non-adherence was defined as taking less than 95% of doses since last pharmacy visit or scheduled clinic-visit dates (>3 days late). In the study, gender (OR: 2.13, 95% CI: 1.37-3.30), structural barriers to clinic attendance score (OR: 1.39, 95% CI: 1.23 -1.56), structural barriers to medication-taking scale (OR: 1.38, 95% CI: 1.23-1.54), and behavioral skills (OR: 1.08, 95% CI: 1.01-1.15) were significantly associated with ART non-adherence(46). While the study provides valuable information about factors associated with HIV medication adherence, findings may be limited due to residual confounding. The study adjusted for only one variable (gender) in logistic regression models. Inability to control for other potential confounders such as dietary intake, SES, ART duration, medication side effects, etc., may have resulted in a significant overestimation of the observed results. Generalizability of these findings may be limited as the study was conducted in an urban setting.

In a cross-sectional study, Senkomago et al. (2011) investigated barriers to ART adherence among 140 adults in Kayunga, Uganda(47). Barriers to ART adherence were assessed through clinic interviews. Patients who reported missing pills were asked to provide explanations for doing so from a list of the following reasons: 1) no transport to clinic, 2) lack of access to food, 3) lack of access to water, 4) forgot, 5) away from the medication at dose's time, and 6) other. ART adherence was measured from

medical records using the pill count method, along with self-report questionnaires administered to patients during interviews. ART adherence was defined as taking 95% or more of prescribed medications for the past six months. In this study, being away from medication at dose time (29.4%) and forgetting to take pills (27.5%) were the main reasons for non-adherence, followed by lack of access to food (11.7%) and transportation costs (7.8%)(47). While the study provided compelling findings regarding medication adherence, there were several limitations. Generalizability of the findings may be limited as study participants were mostly employed and highly educated, thus may not have been representative of the general population. Furthermore, the analytic procedure was not clearly presented in this study therefore it is not clear whether information on confounding variables was collected and adjusted for in regression models. Overestimation of the association between the exposures and ART adherence is likely to occur if significant confounders were not adjusted for in the analysis.

While previous studies have investigated numerous factors associated with ART adherence, studies published to date have had methodological limitations. The reviewed studies investigated these factors in urban settings, and none of them focused on women in general. Our study intends to investigate these factors among women in rural settings in Eswatini using mixed methods, an analytical approach that will enable us to identify the factors that best explain barriers to ART adherence.

2.4.2 Food Insecurity and ART Adherence

Food insecurity is defined as: inadequate access to food of sufficient quantity and quality or the inability to acquire food in socially acceptable ways or “a situation that exists when people lack secure access to sufficient amounts of safe and nutritious food”(43,166). A growing body of evidence indicates that food insecurity increases the risk of HIV transmission, ART nonadherence, and may lead to negative clinical outcomes (such as increased HIV replication, heightened disease progression, reduced viral load suppression, and increased morbidity) among people living with HIV/AIDS(11,13–15). In Swazi

households, women are responsible for ensuring that children and other family members are adequately fed. For women living in poverty, this presents an ongoing challenge. As a coping strategy, some women engage in sex work or inappropriate relationships out of desperation to gain access to food and food-related resources. A study conducted by Weiser et al. (2007) among women in Eswatini and Botswana determined that food insecurity was associated with increased intergenerational sex, and sex exchange for food and money along with inconsistent condom use, all of which increases the risk of HIV infection among women(26). An increase in risky sexual practices as a consequence of food insecurity can also act as a significant barrier to ART adherence(26). Nonadherence to HIV medications results in treatment interruption and missed clinic visits, which lead to increased susceptibility to infections and overall poor health outcomes(14,26,44,48).

HIV/AIDS and food insecurity are becoming increasingly entwined in a vicious cycle, with food insecurity heightening susceptibility to HIV exposure and infection, and HIV/AIDS in turn heightening vulnerability to food insecurity(49–52). Scarce financial resources and insufficient food access coupled with increased demand for care can make it extremely difficult for individuals to prioritize chronic health costs. While the Swazi government provides free ART treatment for all HIV positive patients, individuals living in remote areas often travel to the clinic using public transportation and must pay for transportation out-of-pocket as these costs are not covered by the free government programs. Food insufficiency may result in a shift away from financing long-term health care to spending money on necessities to ensure a stable household food supply(22,49). For example, women with limited financial resources may choose to spend money on food and food-related activities (such as farming) instead of expending scarce financial resource on HIV treatment and care. In a qualitative study in Uganda, researchers found that individuals on ART often had to choose between using their limited income on paying for transportation to the clinic versus being able to adequately feed themselves and their

children. As a result of these difficult choices, some individuals in the study missed health care appointments and were unable to pick up their antiretroviral medications(53).

Additionally, food insecurity can affect ART adherence through the impact of inadequate nutritional intake. Women in poor households may cope with food insecurity by limiting their meal frequency and reducing portion sizes. A study conducted among 357 caregivers in South Africa found that decreasing food variety, reducing portion sizes, and skipping of meals were coping strategies that women used to overcome food insufficiency in the household. Food deprivation and anxiety over food supply can lead to stress, which may contribute to ART nonadherence, increased disease progression, and adverse health outcomes among infected individuals(54).

In a recent prospective study, Weiser et al. (2014) examined the association between household food insecurity and ART adherence among a sample of 438 adults in Mbarara, Uganda(11). Subjects were recruited at the Mbarara Immune Suppressant clinic and were eligible to participate in the study if they lived within 20 kilometers of the clinic. The primary exposure, household food insecurity, was measured using a Household Food Insecurity Access Scale (HFIAS). The study had three primary outcomes: ART adherence, incomplete viral load suppression (HIV-1 viral load > 400 copies/ml), and CD4 cell counts (CD4 cell count < 350 cells/ μ l). ART adherence was assessed using a Self-report Visual Analogue Scale. The assessment was conducted on a quarterly basis over a three year period. Participants were asked to report the quantity of antiretroviral drugs taken in the previous seven days, using a scale of 0-100% with ART non-adherence defined as taking less than 90% of prescribed medication over the period of the study. The study findings illustrated that in adjusted models food insecurity was associated with a 56% increased risk of ART nonadherence (AOR: 1.56, 95% CI: 1.10-2.20), a 52% increased risk of incomplete viral suppression (AOR: 1.52, 95% CI: 1.18–1.96), and a 47% increased risk of CD4 cell count less than 350 cells/ μ l (AOR 1.47, 95% CI: 1.24–1.74), respectively(11). While the study provided valuable information on the effect of food insecurity on ART adherence,

generalizability of the findings may be limited as only participants residing within 20 km from the clinic were included in this study. It is possible that participants living in remote areas experienced transportation challenges (transport availability and cost) that may have hindered their ability to pick-up medication from the clinic and therefore increased the risk of non-adherence. The study findings were also limited due to failure to adjust for important potential confounders such as family and spousal support, medication side effects, and educational level as they have been shown in previous studies to significantly influence ART adherence.

In a recent cross-sectional study, Morojele et al. (2014) investigated structural and social determinants of ART adherence among 305 individuals in Tshwane, South Africa(54). Subjects were recruited at HIV clinics located in Tshwane Metropolitan Municipality, and were deemed eligible to participate if they had been on antiretroviral therapy for at least 4 months. In this study, household food insecurity was measured using a structured questionnaire, and included in regression models as a control variable. The primary outcome, ART adherence, was measured using the CASE adherence index questionnaire, a three-item measure which assesses: (a) difficulty taking ART on time (b) frequency of missed doses, and (c) time since the most recent missed dose. ART non-adherence was defined as having a score of 10 or more on the CASE adherence index scale. In adjusted models, food insecurity was shown to be a significant predictor of ART adherence ($t=2.17$, $p<0.05$)(54). The study had some notable limitations however. Researchers relied on self-reported measurements of ART adherence, which may have been affected by recall bias and could have produced unreliable adherence estimates. This method is subject to human error due to its reliance on subject's memories to estimate the number of days that participants missed medication. The findings may also have been affected by social desirability bias. In this case, participants could have over reported medication adherence in order to impress clinic staff during the interview process. This may have resulted in misclassification of exposure and would have led to an underestimation of the true association between ART adherence and food insecurity.

Generalizability of the findings may also be limited due to the use of a non-standardized measurement tool to assess food insecurity. Food insecurity was measured using a structured questionnaire that had not been validated and may have produced inaccurate estimates due to possible misclassification of exposure.

In another cross sectional study, Hong et al. (2014) examined the associations between food insecurity and ART adherence among 390 HIV- infected participants in Windhoek, Namibia(38). Food insecurity was assessed using a Household Food Insecurity Access Scale through interviews at antiretroviral delivery clinics. The primary outcome, ART adherence, was assessed by clinic staff using the Medication Possession Ratio method, defined as taking 80% or more of prescribed medications for the past twelve months. The study findings indicated significant associations between food insecurity and ART nonadherence (OR: 3.8, 95% CI: 1.65 – 8.95). While the study adjusted for numerous confounding factors, limitations due to selection bias were likely to occur and could have affected generalizability of these findings. In the study, participants were recruited at the clinic during their routine visits and may not have been representative of the general population. Participants who attended routine clinic visits could have been more likely to be adherent to medication. Having a study sample with motivated individuals may have led to an overestimation of ART adherence and would bias the results towards the null.

Though previous studies have shown evidence for the associations between food insecurity and ART adherence, most of these have had methodological limitations, and none were conducted in Eswatini which has the highest HIV prevalence worldwide. Two out of three of the reviewed studies were conducted in urban settings. Additionally, findings from the above studies have limited generalizability, as participants were recruited at clinics. This population would be more likely to be proactive in monitoring their health and may not have been representative of the general population.

2.4.3 Proximity to a Health Facility and ART Adherence

Empirical research has shown that an individual's health status may be influenced by the social and environmental context in which the individual lives(55). The influence of community characteristics, independent of individual and household factors, has been known to exist across a range of public health outcomes, including chronic diseases, health perceptions and behaviors, women's health, and children's health(55–58). Community factors such as location, neighborhood poverty, and availability of a health facility also impact health behaviors(45,55). For example, current evidence indicates that compared to individuals living in urban areas, those living in rural areas are less likely to adhere to medication, and therefore more likely to have poorer health outcomes. Comparatively, urban settings tend to have in place infrastructure that facilitates increased access to public transportation, resulting in greater access to health facilities, which collectively may increase health seeking behavior among HIV infected individuals(36,59). Greater distance to one's health care facility has been associated with poor health care access and negative health outcomes(60). There is significant evidence that shows that health care utilization is lower in rural areas compared to urban areas. Residents of rural areas often have increased travel distance and time compared to urban residents. Longer travel distances and fewer transportation options available in rural areas could be a significant factor influencing medication access and adherence, and may lead to poor health outcomes(60,61).

While the presence of a health facility in a community may facilitate health seeking behaviors, including access to HIV medication and frequent follow-ups, conversely long distance travel to a health facility can pose a significant barrier to accessing treatment services(12,44,62). As with most countries in southern Africa, Eswatini provides free HIV treatment to its HIV positive citizens, distributed through local clinics and hospitals. Individuals receiving ART, however, are required to travel (often long distances) to hospitals or clinics to pick up monthly refills of their medication. For women living in remote villages, traveling long distances can be particularly challenging. Every month they have to take a

day off from work, and if they cannot afford to pay for transportation, are forced to walk to the clinic. The cost of both transportation and time spent traveling can therefore be substantial for rural woman, and often competes with other basic and essential expenses such as food, shelter, and education (school fees and uniforms for their children). In a qualitative study conducted among HIV positive individuals in Eswatini, lack of money for transportation was reported as the main reason patients missed clinic visits(44). The same study discovered that some patients reported having difficulties balancing their need for transportation against the need to pay for food, school fees, and other family necessities. Financial and geographic challenges to health care access could lead to missed appointments and poor adherence to ART.

In a recent cross-sectional study, Wakibi et al. (2011) investigated factors associated with ART adherence among a sample of 416 adults in Nairobi, Kenya(63). Subjects were recruited from three HIV treatment centers and were deemed eligible to participate in the study if they were taking ART for at least three months at the time of the survey. Information on exposure variables (factors affecting ART adherence) was assessed using self-reported interviews at clinics. The primary outcome, ART adherence, was measured using the CASE adherence index questionnaire. Three items were assessed: (a) difficulty taking ART on time (b) frequency of missed doses, and (c) time since the most recent missed dose. ART non-adherence was defined as having a score of 10 or more on the CASE adherence index scale. In adjusted models, proximity to a health facility (authors did not define how proximity to health facility was assessed) was significantly associated with ART adherence (OR: 2.4, 95% CI: 1.16-4.93). Participants who accessed therapy in clinics within a walking distance from their homes were more than twice as likely to be nonadherent than patients who refilled their medication at distant clinics. Researchers in this study were surprised by these findings and suggested that the results may have been affected by socioeconomics and stigma. They reasoned that the study participants who accessed free therapy in clinics within walking distance to their homes did so not for convenience, but because they could not

afford transport costs to alternative ART clinics, and that some participants may have chosen not to refill prescriptions rather than be seen by friends and acquaintances when walking to clinics. The authors did not adjust for social stigma, which may have led to significant bias of the results. While the study provided compelling information regarding the effect of proximity to a health facility on medication adherence, findings may have been limited due to residual confounding. The study adjusted for only two variables (therapy scheduling difficulties and reasons for skipping doses) in logistic regression models. Inability to control for other potential confounders such as age, gender, medication side effects, socioeconomic status, household food security, family size, perceived stigma, mode of transport, and transportation costs may have resulted in a significant overestimation of the observed association. Additionally, the assessment method used to measure proximity to a health facility was not discussed, and it was unclear whether the measurements were self-reported or not. Failure to use objective measurements may have resulted in misclassification of the exposure variable and may have produced inaccurate estimates of distance.

In another cross-sectional study, Uzochukwu et al. (2009) investigated determinants of ART adherence among a sample of 174 adults in Nigeria⁽⁶⁴⁾. Information on exposure variables (determinants of ART adherence) were assessed using semi-structured questionnaires at the clinic. . The primary outcome, ART adherence, was assessed through self-reported interviews. Participants were asked to report if they had missed taking medication in the previous month however ART adherence was not clearly defined in the study. In adjusted models, proximity to a health facility was significantly associated with ART adherence ($t=0.685$, $p<0.05$)⁶⁴. The researchers found that participants who travelled more than 20km to the clinic were more likely to be nonadherent to ART than those who lived close to the clinic. As with the study by Wakibi et al. (2011), findings may have been biased due to residual confounding. The study controlled for a limited number of confounding factors in logistic models (sex, age, marital status, education, employment status, and household income). Generalizability

of the findings may also be limited due to the use of an unreliable measurement tool to assess ART adherence. ART adherence was measured using a semi-structured questionnaire that had not been validated (either in the study or in the literature) as a reliable measurement tool for assessing ART adherence. Failure to use a validated measurement tool may have resulted in misclassification of the outcome variable and may have produced inaccurate estimates of ART adherence. Furthermore, measurements of proximity to a health facility were not described in this study.

In a recent case-control study conducted in Ethiopia, Berhe et al. (2013) investigated the effect of nutritional factors on ART adherence among 174 HIV positive individuals. In this study, travel distance to a health facility ($\leq 10\text{km}$ or $>10\text{km}$) was assessed using a structured questionnaire and included in regression models as a control variable. Once again, the authors fail to identify how proximity to a health facility was measured. The primary outcome, ART adherence, was assessed using self-report structured questionnaires. Patients who reported taking less than 95% of prescribed antiretroviral medication for the previous month were classified as “cases”. Patients who reported taking more than 95% of prescribed antiretroviral medication for the previous month were classified as “controls”. Findings from this study showed a nonsignificant association between distance travelled to a health facility and ART adherence (OR: 1.9, 95% CI: 0.8-10.3)(65).

In another cross-sectional study, Carlucci et al. (2008) investigated predictors of ART adherence among a sample of 424 adults in Zambia. Participants were recruited at three antiretroviral clinics, and were deemed eligible to participate if they had been on antiretroviral therapy for at least one month. The primary exposure, distance travelled to a health facility, was measured using Global Positioning System (GPS) and maps. The primary outcome, ART adherence, was assessed by clinic staff using the Medication Possession Ratio method, defined as taking 95% or more of prescribed medications for the past five months. Similar to the study conducted by Berhe et al., results from this study indicated a nonsignificant association between distance travelled to a health facility and ART adherence ($p>0.05$)⁶⁷.

While community level factors have been shown to impact health behaviors, few studies have investigated the effect of proximity to a health facility on ART adherence. Findings from these studies have been conflicting with some illustrating significant associations between proximity to a health facility and ART adherence(63,64,66), and others demonstrating a non-significant association(65,67). Additionally, participants in all the studies were recruited during routine clinic visits, and therefore may not be representative of the general population.

2.5 Mixed Methods Methodology

2.5.1 Mixed Methods Studies

Creswell defines a mixed methods design as an approach that “involves the collection or analysis of both quantitative and/or qualitative data in a single study in which the data are collected concurrently or sequentially, are given a priority, and involve the integration of the data at one or more stages in the process of research” (68). It is a method that allows researchers to use the strengths of both qualitative and quantitative analysis techniques in order to obtain a richer and in-depth understanding of research questions or phenomenon(68).

Researchers have used mixed methods for the following purposes: 1) triangulation (seeks convergence and corroboration of results from different methods studying the same phenomenon) , 2) complementary (seeks elaboration, enhancement, illustration, and clarification of the results from one method with the results of another method), 3) development (uses results from one method to help inform another method), 4) initiation (discovering paradoxes and contradictions that lead to a reframing of a research question) and 5) expansion (seeking to expend the breath and range of inquiry by using different methods for different enquiry components)(69).

2.5.2 Mixed Methods Designs

Approaches to mixed methods studies differ on the basis of the sequence in which the components occur and the emphasis given to each. The qualitative and quantitative components may be performed concurrently or sequentially, and emphasis may be placed on either component or equal weight may be given to both(70). For instance, a preliminary qualitative component may serve to generate hypotheses or to develop the content for a questionnaire to be used in a follow-up quantitative study. Conversely, a preliminary quantitative component may generate surprising or inconsistent findings that may be examined in greater depth with a follow-up qualitative component(70).

Mixed methods can be classified into six major designs (Figure 3)(70):

1) Sequential Explanatory Design: has two data collection phases. It involves the collection and analysis of quantitative data followed by the collection and analysis of qualitative data. This design is often used by researchers to explain and interpret findings of a quantitative study.

2) Sequential Exploratory Design: is another two phase design in which qualitative data is collected and analyzed followed by a phase of quantitative data collection and analysis. The findings of these two phases are then integrated, and priority is often given to the qualitative aspect of the study.

3) Sequential Transformative Design: has two distinct data collection phases, one following the other. In this design either the qualitative or quantitative method may be used first. Priority may be given to either phase.

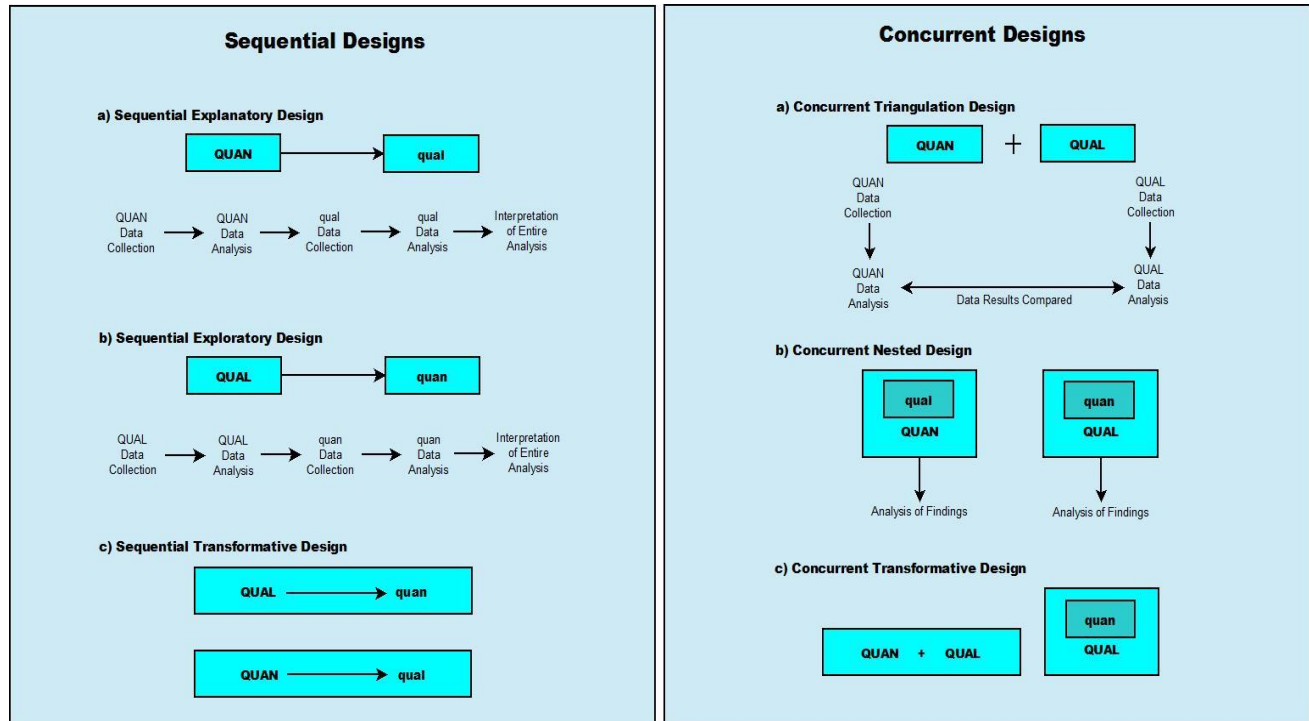
4) Concurrent Triangulation Design: has one data collection phase in which quantitative and qualitative data are collected concurrently. Ideally, priority would be equivalent between the two methods, but in practical application priority may be given to either the quantitative or the qualitative approach.

5) Concurrent Embedded/Nested Design: is similar to the concurrent triangulation design. This design employs one data collection phase during which quantitative and qualitative data are collected simultaneously. Unlike the traditional triangulation design, a nested design has a predominant method that guides the project. The method given less priority (quantitative or qualitative) is nested within the predominant method (qualitative or quantitative).

6) Concurrent Transformative Design: may take on the design features of either a triangulation or nested design in which the two types of data are collected concurrently during one data collection phase and may have equal or unequal priority.

Mixed methods have been used in numerous studies of health research, including cardiology(71), mental health(72), cancer (73), and public health nutrition(74). These techniques have allowed researchers to explore and understand complex determinants of health and to uncover beliefs, experiences, and motivations underlying individual health behaviors.

Figure 3: Mixed Methods Designs



Source: Creswell JW et al., 2003

2.6 Social Ecological Model

The social ecological model (SEM) is based on premise that behavior has multiple levels of influence and that no single factor can explain why some individuals in similar environments are at higher risk of ART nonadherence, while others are not(45,75,76). In this model, ART adherence is viewed as the outcome of an interaction among numerous factors operating at three levels: the individual-, the household-, and the community level. This approach is more likely to sustain ART compliance overtime than any single intervention.

2.6.1 The Individual level

This level identifies intrapersonal influences of ART adherence. It includes personal history and biological factors that are unique to the individual, such as women's experiences, feelings, and attitudes towards ART. These factors impact how individuals behave and may have a direct influence on ART

adherence.

2.6.2 The Household level

The household level examines the household environment, social and interpersonal factors (including relationships with various persons or groups such as family, friends, spouses, and sexual partners) that act as barriers or facilitators of ART adherence. Individuals from one's social network, partners and family members may influence a person's behavior and contribute to their perception regarding treatment, which may impact access and utilization of ART and ART-related services.

2.6.3 The Community level

This level explores the structural and institutional influences of ART adherence. Community structures are often important in determining how populations behave and what customs they uphold. Therefore, it is important to understand the traditions and cultures within a community to determine where health behaviors originate. In addition to interpersonal relationships, geographical or the environmental context in which social relationships occur (such as communities, churches, non-governmental organizations, community-based organizations, healthcare facilities and workplaces) also influence ART adherence. They affect factors at the household and individual levels that impact health behaviors, and are important explanatory factors of ART adherence. This means that based on availability of resources and sustainable developments in certain communities, community structures (such as clinics/hospitals, roads, etc) have the ability to have a positive impact on individual health outcomes.

The assumption for this framework is that ART adherence for women will be influenced by factors operating at multiple levels. The focus of this study is to examine the influences of household food insecurity, proximity to a health facility, and transportation costs on ART adherence. This

framework has been used by researchers in public health to describe factors within multiple domains that exert an influence on individual health outcomes(69,76).

CHAPTER 3

PURPOSE OF THE STUDY

3.1 Purpose of the Study

Eswatini has the highest HIV prevalence in the world (27.2%), with the prevalence being higher among adult women than men(3). It is estimated that 84% of infected adults in Eswatini are receiving ART, yet data on ART adherence and its associated factors is very limited, particularly for infected women in rural settings, a highly vulnerable subpopulation of women living with HIV. This study examined associations between household food insecurity, proximity to a health facility, and ART adherence of HIV-infected women living in rural Eswatini.

3.2 Research Questions

Question 1: What intrapersonal, social, and structural barriers to ART adherence do HIV positive women in rural settings identify?

Question 2: Does food insecurity play a significant role on ART adherence among HIV-infected women in rural settings?

Question 3: Does proximity to a health facility significantly affect ART adherence among HIV-infected women?

3.3 Hypotheses and Specific Aims

Our research questions will be examined by pursuing the following specific aims and hypotheses:

Aim 1:

To identify intrapersonal, social, and structural factors perceived by HIV-infected women as barriers to ART adherence.

Hypothesis: This aim is exploratory in nature; therefore we do not have a definitive hypothesis about the outcome.

Aim 2:

To assess the role of household food insecurity on ART adherence among HIV-infected women.

Hypothesis: We hypothesize that women living in food insecure households (households with limited access to sufficient quantity and variety of foods) will be less likely to adhere to ART.

Aim 3:

To examine the influence of proximity to a health facility on ART adherence among HIV-infected women.

Hypothesis 3a: We hypothesize that women living in communities closer to a health facility will be more likely to adhere to ART compared to those living in remote areas.

Hypothesis 3b: We hypothesize that ART nonadherence may increase with higher transportation costs.

Aim 4:

To discuss issues of food insecurity as they relate to HIV/AIDS and policy development in Eswatini.

Hypothesis: This aim seeks to provide context regarding food insecurity and HIV/AIDS in Eswatini, therefore no definitive hypothesis is presented.

3.4 Rationale and Significance of the Study

Adherence to treatment regimens is clearly important to the long-term success of comprehensive HIV care. Retention of patients on ART is the most important component of therapy essential to decreasing transmission of the disease and improving the quality of life for people living with HIV. Currently, Eswatini is faced with the problem of an increasing number of patients that are *defaulting on treatment as treatment duration increases*, despite government efforts to provide free HIV

medications, as well as increased access to HIV treatment and care health facilities throughout the country. According to a report by the Eswatini Ministry of Health, lack of compliance to HIV treatment and care is one of the primary challenges facing HIV programs in Eswatini (77,78), yet there is limited scientific data regarding ART adherence and its associated factors.

Women living in poverty in rural settings seem to be at particular risk as a result of social-cultural and environmental factors. While previous studies have investigated numerous factors associated with ART adherence, they have not assessed variables that promote or hinder adherence to ART for infected women living in rural settings, such as food insecurity (a highly prevalent risk factor particularly among rural households). It is therefore essential to identify factors associated with ART adherence in order to provide empirical data that will help reveal the challenges that women living with HIV face regarding HIV treatment. To our knowledge, this may be the first study to investigate factors associated with ART adherence among rural women in Eswatini.

In conducting this study we identified barriers to ART adherence for HIV-infected women, with a specific focus on clarifying the critical association between food insecurity and proximity to health care facilities to ART adherence. Additionally, participants in our study were recruited from rural communities rather than at clinics/hospitals, which provided us with a more representative sample and thereby improved generalizability of our findings. Findings from this study may help inform policies to resolve structural and social barriers to ART adherence among rural women, a highly vulnerable population to treatment failure, poor health outcomes, and early mortality. The study also provides important knowledge for devising sustainable food security interventions to be integrated into HIV/AIDS programming.

CHAPTER 4

MATERIALS AND METHODS

4.1 Study Population and Setting

This study was conducted in Eswatini, a small (17,364 km²) country in sub-Saharan Africa, with an estimated population of 1.34 million, 63% of which resides in rural settings(79). The country is divided into four main geographic regions: Hhohho, Manzini, Shiselweni, and Lubombo. The study was conducted in collaboration with four health facilities located in the Lubombo and Shiselweni regions. Two of these facilities are government funded and two are primarily funded by charity organizations. All four facilities collaborate closely with numerous international non-governmental organizations (NGOs). These clinics serve approximately 1500-1700 patients each. Three of the four facilities provide counseling services related to HIV diagnosis, medical care, and ART at no cost to their patients. The remaining clinic provides similar services but charges a small fee (R5.00, approximately \$0.40 US) per visit. In addition, all clinics provide therapeutic and nutritional support through the World Food Program Food by Prescription initiative. This program aims to improve nutritional status and health outcomes for undernourished patients undergoing tuberculosis or anti-retroviral treatment. Eligibility for program enrollment is determined by assessment of Body Mass Index (BMI) and Mid-Upper Arm Circumference (MUAC). Individuals with a BMI<18.5 and MUAC<23 are provided with a monthly ration of maize (staple for traditional meals), peas, vegetable oil, and a corn soya blend called Supercereal(80).

4.2 Treatment and Care Management

Clinic visits

In 2016, the Eswatini government introduced community-centered ART delivery models (Comm ART) intended to improve ART compliance and reduce the number of patients that are lost to follow up.

These models include: community-based ART groups, teen clubs, and ART outreach models. Detailed information about the different Comm ART delivery models can be found in the referenced document(81). As part of this program, mobile clinic vans travel into underserved rural villages where clinic personnel and community expert clients (trained lay health workers residing within the community) provide medical services to patients(80). Additionally, community expert clients are also charged with reaching out to patients who have defaulted on treatment, with the goal of resuming regular care. Patients initially diagnosed with HIV are enrolled in lifelong care and evaluated on a regular basis.

During the first 6 months after initiating ART, patients are instructed to attend monthly clinic visits for monitoring their status and to retrieve medication. Patients that are evaluated as stable after 12 months of clinic visits are enrolled into Comm ART, where they are eligible for a three month supply of medication per visit, while unstable patients are required to continue monthly assessments at the clinic. Patients are classified as stable if they have been on ART for at least a year, have not missed clinic appointments, and have undetectable viral loads from the most recent consecutive tests (with the most recent test taken within the past six months). During initial clinic registration, patients are asked for consent to contact their treatment supporter (typically a friend/relative aware of their HIV status) in the event of a missed appointment. If a patient fails to attend a scheduled appointment, clinic staff (usually expert clients) attempt contact via text message or by phone to arrange for patient's return to care. In cases where the patient is lost-to-follow-up, they are referred to community expert clients who track down the patient and conduct follow-up home visits.

Adherence

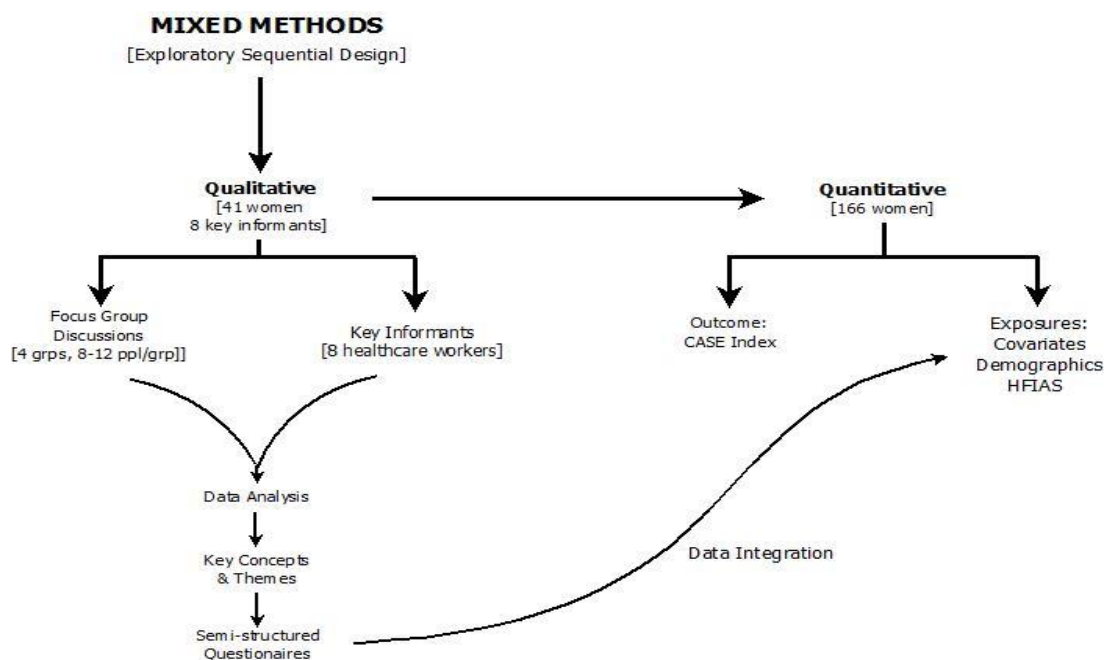
Adherence, measured through pill count, is assessed every time a patient receives medication either at the clinic or during Comm ART visits. For adherence assessments, patients must bring their remaining medication to each visit for counting by the clinic staff or expert clients. Adherence

counseling is provided before ART initiation and reinforced at each subsequent follow-up visit. Patients who miss doses frequently (e.g. 2-3 times per week) are provided additional counseling sessions intended to motivate consistency in medication adherence.

4.3 Study Design

We conducted a cross-sectional study to investigate barriers to ART adherence among HIV-infected women in rural Eswatini, using a mixed methods approach. This study was conducted in collaboration with health facilities in the Lubombo and Shiselweni regions between May to November, 2017. We used a sequential exploratory design (a methodology with two data collection phases) to investigate barriers to ART adherence among HIV-infected rural women. In the first phase, we collected and analyzed qualitative data. Findings from the qualitative data analysis informed and shaped the survey questionnaire that was used to collect quantitative data in the second phase of the study (Figure 4).

Figure 4: Mixed Methods Study Design



*CASE Index: CASE adherence index questionnaire, tool for assessing ART adherence.

*HFIAS: Household Food Insecurity Access Scales, tool for assessing household food insecurity.

4.4 Sampling and Participants Recruitment

For the qualitative phase, we employed a convenience purposeful sampling technique to recruit participants into the study. Participants were recruited in collaboration with local health facilities and community health workers or expert clients. The research team, which consisted of the Principal Investigator (PI) and two research assistants (RAs), visited the health facilities and worked with community health workers to identify target communities. Once target communities were identified, the research team attended community outreach activities and support group meetings in those communities where they introduced the study to potential participants. Women who were interested were invited to participate in a focus group discussion (FGD) session and survey. In addition, the research team employed a snowball sampling technique and worked with local community health workers (expert clients) to recruit other qualifying individuals to participate in the surveys. During recruitment, it was emphasized that participation in the study was entirely voluntary, that all interviews were confidential, and patients' willingness to participate would have no effect on their treatment at the clinic. Participants were compensated with a R100 for traveling expenses and for time taken to participate in the study. Healthcare workers (including nurses and expert clients) were recruited as key informants, using purposeful sampling.

4.4.1 Eligibility Criteria

The study population consisted of rural HIV-infected Swazi women receiving HIV antiretroviral therapy. Women were eligible to participate in the study if they had been on ART for at least a month (at the time of the focus group discussions and survey interviews), and were between ages 20-49 years. The study focused on women of child-bearing age because they are the most vulnerable to HIV infections and oppressive cultural traditions. By targeting this age group, we acquired reliable information to help answer our research questions and hypotheses in a comprehensive manner.

4.4.2 Sample Size for Qualitative Data

We conducted FGDs of 41 women and individual interviews of 8 key informants. Sample size for focus groups and key informant interviews was determined by the point when data saturation was reached. Data saturation was reached when the ability to code and obtain additional new information was attained. After reviewing the literature, we determined that a sample size of 30-50 was regarded as sufficient to reach saturation for doctoral studies (83).

4.4.3 Sample Size for Quantitative Data

From the population of women receiving ART, we selected a sample of 166 individuals. G*Power statistical software was used to calculate the sample size based on the following estimates: a moderate effect size of 0.3, $\alpha=0.05$, and power=0.95. The results yielded an estimated sample size of 138 participants, which is comparable to prior mixed methods studies of ART adherence (84,85).

4.4.4 Pilot Testing: Qualitative and Quantitative

Separate pilot studies were conducted for the qualitative and quantitative phases of the study. The qualitative pilot study FGD comprised of 5 rural HIV-infected women in May 2017. The quantitative pilot study comprised of in-person surveys with 12 rural HIV-infected women in October 2017. These pilot studies were conducted at neighborhood care points in rural communities in the Shiselweni region. The purpose of the pilot was to test feasibility and validity of our measurement instruments and methods of analysis, as well as to ascertain logistics regarding general study implementation. During data collection and analysis, members of the field team (PI and two RAs) held several debriefing sessions where implementation of various components of the study were reviewed and reflected upon for consistency and practicality. Any clarifications, suggestions, and coding discrepancies that arose were resolved through research team discussions. Thereafter, measurement instruments and data analysis procedures were reviewed and modified as necessary. All study protocols were established before the commencement of main data collection.

4.5 Qualitative Data Collection

We conducted four FGDs (8-12 women per group) and in-depth interviews of key informants (8 healthcare workers) in June 2017. Key informants interviews were conducted at the clinic while FGDs were conducted in a central location such as local constituency building, churches, or neighborhood care points within respective rural communities. Key informants were asked to reflect on their observations and perspectives regarding barriers to ART adherence in their respective communities (Appendix A). Consent (in the local language of siSwati) was obtained from participants at the time of the interviews or FGD sessions. The research team read and explained the consent form passed out to study participants. Study participants were provided time to ask questions/clarify content, and if they agreed to participate in the study, signed the written consent. Participants of the FGD also provided demographic data including: age, area of residence, marital status, and educational background.

The purpose of the focus group was to collect in-depth data on women's lived experiences that included perspectives and practices regarding ART, with emphasis on identifying barriers and challenges to adherence, and to specify in what ways these barriers impacted adherence to their ART intake regime. The focus groups were conducted by the PI (Becker) using a moderator's guide consisting of semi-structured questions to facilitate group discussions, allowing for discussion of emergent relevant and related topics (Appendix B). Specifically, participants were asked to reflect on the following: 1) individual, interpersonal, social, and structural barriers to ART adherence, 2) feelings about and experiences with ART, 3) challenges in ART service provision, 4) social support network, and 5) personal beliefs and societal norms as they relate to ART. The focus group discussions were digitally audio-recorded. The recordings were transcribed verbatim in siSwati and then translated to English. All transcribed data was encrypted and stored on a password protected computer.

4.6 Quantitative Data Collection

Quantitative data was collected from medical records and through an interviewer-administered survey questionnaire (n=166), see Appendix C. Signed consent was obtained to access records and for the survey participation. The surveys were conducted in a central location such as local constituency building, churches, or neighborhood care points within respective rural communities. Study participants were interviewed in their native language of siSwati by trained personnel, using validated questionnaires that had been modified to include questions shaped by the findings from the qualitative data. The survey included the following questionnaires: 1) Household Food Insecurity Access Scales, 2) CASE adherence index questionnaire, and 3) a semi-structured questionnaire including covariates, demographic information, and questions on barriers to ART adherence identified by women and key informants from focus group discussions.

4.6.1 Outcome Assessment

ART adherence was measured using the CASE adherence index questionnaire, a three-item measure which assesses: (a) difficulty taking ART on time, (b) frequency of missed doses, and (c) time since the most recent missed dose.

4.6.1.1 Outcome Parameterization

In the CASE adherence index questionnaire, each response was assigned a score and women who had an index score greater than 10 were classified as being adherent and those with an index score less than 10 were classified as being nonadherent (Appendix D). The outcome was modeled as a dichotomous variable (ART adherence vs ART nonadherence).

4.6.1.2 Validity of Outcome Assessment

Self-reported ART adherence was pilot tested prior to data collection. Structured questionnaires have been used in previous studies to gather information on HIV medication adherence. Previous

studies have demonstrated that this measure is able to distinguish medication adherence from nonadherence among individuals in international settings(38,46,54).

4.6.2 Exposure Assessment: Household Food Insecurity

Data on household food insecurity was collected by trained personnel using Household Food Insecurity Access Scales (HFIAS)(86). Participants were asked to provide information on their household food status in the month before the survey. Women were interviewed on all three domains of the HFIAS questionnaire: 1) anxiety and uncertainty about the household food supply, 2) insufficient food intake, and 3) insufficient quality of food.

As part of the interviewer-administered questionnaire, participants were also asked “In the past month, have you ever skipped taking your ARVs because of any of the following reasons: hunger, hunger-related side effects, poor treatment, forgetfulness, stress, clinic too far, no money for transport, etc”. Responses to these questions were identified as barriers to ART adherence, and were modeled as dichotomous variables (e.g. hunger: yes/no).

4.6.2.1 Exposure Parameterization

Women were classified as food insecure if they answered yes to one or more of the food insecurity questions. Household food insecurity was modeled as a dichotomous variable (food secure vs moderately food insecure, mildly food insecure, and severely food insecure).

4.6.2.2 Validity of Exposure Assessment

HFIAS is an established scale designed to assess household food insecurity in multiple international settings(86). Previous studies conducted in Africa have demonstrated that this measure is able to distinguish food secure from food insecure households across different cultural contexts(38,42,87).

4.6.3 Exposure Assessment: Proximity to a Health Facility

4.6.3.1 Exposure Data Collection: Travel Time, Transportation Cost, and Mode of Transport

Participants were interviewed using a structured questionnaire regarding mode of transportation (walking or public transportation) they used during the time of their last clinic visit. Individuals who reported taking public transportation were probed to report the amount they paid for transportation. In the same questionnaire, participants were also asked to estimate travel time to and from the clinic or facility where they received health services. We had initially proposed to also measure actual distance from participants' homesteads. However, due to the sensitivity of the subject matter and the stigma associated with HIV in these communities, none of the study participants were comfortable with providing detailed information regarding the location of their homes.

4.6.3.2 Exposure Parameterization

Travel time and transportation cost were modeled as continuous variables while mode of transport was modeled as a dichotomous variable (walking vs bus).

4.6.3.3 Validity of Exposure Assessment

Semi structured questionnaires are validated tools designed to obtain information on demographic and behavioral habits of individuals. These tools have been used in previous studies to gather information on location of individuals across different cultural contexts^{31,67,87}.

4.6.4 Demographics and Covariates Assessment

4.6.4.1 Covariates Data Collection

Factors known to have a significant effect on ART adherence were selected as covariates. Demographics and behavioral habit data were also collected. Women were interviewed using structured questionnaires collecting basic information including: age, household income, marital status, educational level, employment status, ART duration, HIV medication side effects, stigma, HIV disclosure status, alcohol use, ART refills, family size, health status, relationship status, husband/partner's HIV

status, family support, community support, and other covariates identified after the analysis of qualitative data such as hunger-related side effects, general medication side effects, poor treatment, forgetfulness, stress, clinic too far, no money for transport, pills too loud, pills too many, longlines at clinic, being gossiped about, and feeling avoided.

4.6.4.2 Covariates Parameterization

Covariates were modeled as continuous variables: such as age, family size, and ART duration; dichotomous variables: HIV medication side effects, stigma, HIV disclosure status, alcohol use, ART refills, health status, relationship status, husband/partner's HIV status, family support, community support, hunger, hunger-related side effects, general medication side effects, poor treatment, forgetfulness, stress, clinic too far, no money for transport, pill containers too loud, pills too many, longlines at clinic, being gossiped about, and feeling avoided; and ordinal variables: educational level, marital status, and employment status (Appendix C).

4.6.4.3 Validity of Covariates Assessment

Semi structured questionnaires are validated tools designed to obtain a variety of information of individuals across age groups. This tool has been used in previous studies to gather health and nutritional related information of individuals across different settings(11,37,51).

4.7 Qualitative Data Analysis

Phase one of data analysis consisted of each member of the field team (PI and two RAs) independently coding all data sources (key informant interview transcripts, transcripts of FGDs, and observational notes) using Nvivo version 15. Coding consisted of reviewing of transcripts line-by-line to isolate key words and phrases identifying barriers to ART adherence, using an open coding approach to generate emerging themes and nodes(69,88). As identifiers became apparent, codes linked to associated nodes were assigned to each incident of the word/phrase in the source documents.

In the second phase of the analysis, the field team (PI and three RAs) reviewed divergent and convergent emerging themes, reaching consensus on themes. An initial codebook was created, containing clear definitions for each code with examples of their application within the transcripts. Next, the PI and a fourth RA independently applied the codebook to a smaller set of transcripts and reviewed for consistency. This process was carried out twice again, first with a previously unused set of transcripts and then with the full set of transcripts. Coding inconsistencies were resolved through research team discussions and the codebook was adjusted accordingly.

Finally, data was triangulated (adding observational notes) to ensure consistency and ascertain validity of the findings. Employing the process of inter-coder agreement, the research team did a side-by-side comparison of all coded material, again to identify convergent and divergent findings(69). Using the codebook, we thoroughly reviewed all coded text passages to determine whether codes assigned to text passages were similar or different. Coding comparison queries were used to develop percentages of codes that were either similar or different, and reliability statistics (kappas) were computed for systematic data comparisons.

After this step of analysis, we applied a deductive approach to the data whereby codes were grouped into themes related to the social ecological model. This was done through axial coding, where the main themes that emerged from open coding of the data were interconnected with each other and interpreted using the social ecological model(88). Findings from this analysis were documented and used to inform the development of a survey questionnaire used for quantitative data collection.

4.8 Data Integration

Mixed methods design requires an integration of quantitative and qualitative research methods within a given stage of the research process. Integration may occur in several ways: 1) at the study design level (within the research questions e.g., when both quantitative and qualitative questions are

presented), 2) at the methods/analysis level (within data collection such as using open-ended questions on a structured instrument, and within data analysis such as transforming qualitative themes into quantitative items), and 3) at the interpretation and reporting level (such as examining quantitative and qualitative results for convergence of findings)(29,30). This study integrated qualitative and quantitative data at the methods/analysis level through the “building” method, where findings from qualitative data analysis were used to inform the development of the study’s a survey questionnaire, used to collect quantitative data (29,30).

4.8 Quantitative Data Analysis

Data analysis was conducted at the descriptive, univariate, and multivariate levels. Continuous variables are presented as means with standard deviations, and categorical variables are presented as frequencies and percentages.

The majority of categorical variables were fairly distributed. Notable outliers were household food insecurity, general medication side effects, pills too loud, too many pills, and long lines at the clinic. Since household food insecurity (our main exposure variable) was highly prevalent in the sampled communities, there was very little variation in the household food insecurity variable, as only 1.2% of the women were from food secure households. Therefore the variable “hunger” was used as the main exposure variable as its distribution was a better fit for the model. Additionally, using hunger as a proxy variable for household food insecurity helped demonstrate the gravity of the situation in these communities and the direct effect of food insecurity on ART adherence.

For continuous variables, the Kolmogorov-Smornov and Shapiro-Wilk tests were conducted to determine whether data was normally distributed. Travel time and transportation costs were not normally distributed, therefore data were transformed to its natural logarithm. Pairwise correlation tests were conducted to determine whether there was collinearity between selected exposure variables (hunger, hunger-related side effects, gossip, avoided, stigma), and none were found to be correlated.

Univariate analyses were conducted for each variable. Pearson's chi square test of significance was performed to examine associations between the outcome variable (ART adherence) and covariates. Differences in characteristics between women who were adherent versus those who were nonadherent were assessed using the chi square test for categorical variables, and the t-test test for continuous variables. The Fischer exact test was used whenever an expected cell count was less than 5. Variables that were significantly associated with ART adherence at the 25% level of significance were selected and included in the next step of analysis.

Multivariable logistic regression models were used to assess the relationship between ART adherence and hunger, while controlling for other predictors in the model. The backward elimination approach was used to determine variables to be included in the final multivariate model. First, an initial multivariable model was fitted which comprised of all variables with a p-value less than 0.25 at the univariate analysis. Next, we assessed the importance of each covariate based on the p-value of its Wald test. Variables that did not contribute at $p < 0.05$ level of significance were eliminated one at a time and a new model was fitted. The likelihood ratio (LR) test was used for model comparison. Whenever the LR test p-value was greater than 0.05, variables were removed from the model. All variables that were significant at $p < 0.05$ were kept in the final multivariable logistic regression model. All quantitative data were analyzed using STATA version 15 (College Station, TX: StataCorp LP).

4.9 Ethical Clearance

Study approval was obtained from the University of Massachusetts Amherst Institutional Review Board and the Eswatini National Health Research Review Board. Permission to conduct the study was also obtained from the Eswatini Ministry of Health and participating health facilities (Appendix E).

CHAPTER 5

MANUSCRIPT 1

INDIVIDUAL, HOUSEHOLD, AND COMMUNITY LEVEL BARRIERS TO ART ADHERENCE AMONG WOMEN IN RURAL ESWATINI

5.1 Introduction

More than four decades into the HIV/AIDS crisis, an estimated 36.9 million people around the world are HIV-infected, with sub-Saharan Africa accounting for 71% of the global burden(1). Current evidence suggests HIV prevalence rate is highest in Eswatini (formerly known as Swaziland) at 27.4%(89), where incidence rate is estimated at 1.4%, and is nearly twice as high among women compared to men(3).

The disproportionate impact of the epidemic on women in Eswatini is attributable to multiple risk factors including biological, social, behavioral, and socioeconomic vulnerabilities(23). Moreover, Swazi people practice traditional customs which inherently marginalize and oppress women, particularly in rural areas. Men typically regulate distribution of family financial resources, imposing major decisions regarding food and household expenditures, leaving women financially dependent on their husbands/partners for survival, and negatively affecting women's access to HIV treatment. Furthermore, poverty and gender disparities exacerbate HIV transmission by reducing a woman's control regarding issues of safe sex negotiation and sexual rights(23).

Treatments for HIV can improve immune functionality and decrease morbidity and mortality, offering hope that HIV/AIDS can be effectively managed. For antiretroviral medications (ART/ ARVs) to work effectively and efficiently in preventing the risk of HIV transmission and progression to AIDS, they must be taken consistently as prescribed. Patients must be routinely monitored and optimal adherence

achieved in order to reach and maintain viral load suppression(31,32). Optimal level of adherence to ART has been shown to be one of the vital components of achieving viral load suppression and avoiding viral rebound among HIV positive individuals. In a quantitative study of ART patients in Uganda, researchers found a 25% increase in odds of viral rebound among individuals who experienced adherence interruptions(33).

In Eswatini, the government provides free antiretrovirals and clinical treatment to all HIV positive individuals, with an estimated 84% of citizens living with HIV receiving medication(77). Over the past decade, the Ministry of Health, in collaboration with non-governmental organizations (NGOs) and the private sector, has implemented strategies to increase ART coverage and decentralization of HIV care services to regional health facilities, especially in rural areas. Despite this high level of access to treatment, the Ministry of Health in Eswatini identifies nonadherence to HIV treatment as a critical challenge to managing the HIV pandemic(77).

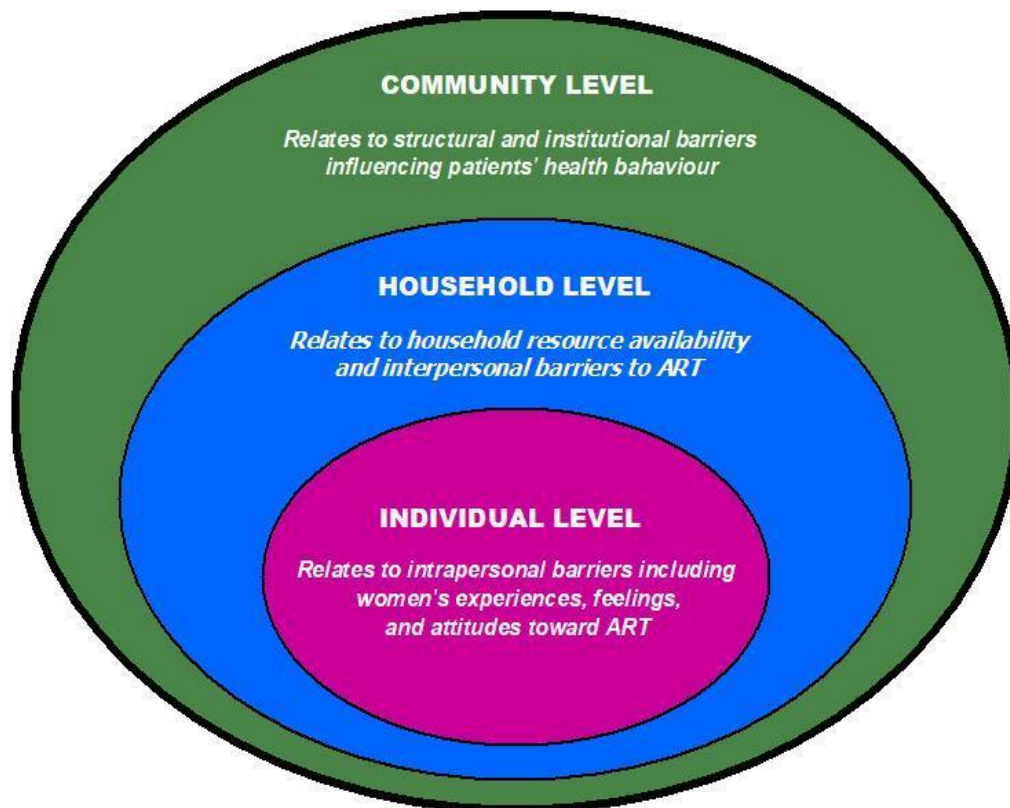
Epidemiological studies have reported high levels of nonadherence to ART in sub-Saharan Africa, with rates ranging from 17.1 to 46% among countries in this region(37,40,47,66). A study conducted of HIV-infected pregnant women in Eswatini reported ART nonadherence to be 50%(41). From a public health perspective, achieving and maintaining optimal adherence among treated individuals is crucial, not only for preventing new infections but also for preventing transmission of drug-resistant HIV. Currently, the percentage of patients remaining on treatment after ART initiation tends to decrease over time (i.e. as duration on ART increases, ART retention rates decrease)(90). Declining retention rates and nonadherence to ART pose significant challenges to HIV treatment and management, particularly for women in their childbearing years since it can negatively impact the prevention of mother-to-child transmission of the disease.

In tackling the problem of treatment defaulters, the Eswatini government recently implemented community-centered ART service delivery models. Known as Comm ART, this service is aimed at increasing access to ART and improving retention rates for all HIV positive patients, particularly those in remote areas(81). However, for these programs to be successful in ensuring treatment adherence and patients' retention to care, it is critical to investigate and identify factors that may facilitate or inhibit patients' access and utilization of treatment. In an effort to eradicate HIV, Eswatini has adopted the UNAIDS 90/90/90 targets to ensure that 90% of HIV positive individuals know their status, 90% of those eligible receive ART, and 90% of those on treatment achieve viral suppression. These new targets are aimed at helping to reach the government's goal of zero new infections and an end to AIDS by 2022(90). And if Eswatini is to achieve zero new HIV infections by 2022(90), near perfect adherence is required for HIV medications to effectively decrease viral load and prevent the spread of HIV(5). Yet studies investigating barriers to ART adherence in Eswatini are scarce. Most notably, there is a lack of research regarding rural women in Eswatini, who are currently the country's most vulnerable to HIV infections.

Health behaviors are better understood with the use of a theoretical framework that takes into consideration complex ecological dynamics and their interaction with individual factors. The social ecological model (SEM) is used in public health to understand the manner in which factors within multiple environmental domains exert an influence on individual health behaviors and outcomes(44,45,47). While HIV studies have elucidated factors that facilitate or hinder optimal HIV treatment, no known studies have focused on the factors that influence ART adherence among women in rural Eswatini and very few studies locally/regionally have used the SEM to investigate influences of ART adherence beyond the individual level. Improving ART adherence and reducing morbidity of women living with HIV requires addressing not only individual-level influences on health, but examining these factors within the environmental context in which women live. Our study speaks to that in a comprehensive manner, and also provides important information to help us understand the complex

behavioral influences of ART adherence in a country with the highest HIV prevalence in the world and the highest AIDS mortality rates in the region. Therefore, the purpose of this study was to identify factors associated with ART adherence in order to provide empirical data identifying the barriers faced by women living with HIV in rural settings with regards to HIV treatment. Furthermore, the study applies a social ecological framework to examine intrapersonal, sociocultural and structural factors associated with HIV care and management, and to further explore how these factors across multiple levels interact and influence ART adherence (Figure 5).

Figure 5: The Social Ecological Model



5.2 Methods

See Chapter 4 for detailed information on the study methods.

5.3 Findings

Data for this study was collected from focus group discussions with 41 rural women receiving ART and in-depth interviews with healthcare workers (n=8). All of the healthcare workers interviewed had extensive daily contact with ART patients, two were nurses and six were expert clients.

Almost half of the focus group participants were married (46.3%), with mean age of 36 years (Table 2). Of the 41 women, 18% had not received any formal education, 39% attended some primary school, and 39% had attended some high school. Most of the women discussed being unemployed or struggling to find work. Some worked seasonally at local clothing factories or sugarcane fields. Of the 41 women, 78% occasionally obtained food and/or financial support from family members (including husbands, partners, and relatives), 10% occasionally received help from neighbors and friends, and 12% of the women said they received no food or financial support from anyone. All the women interviewed reside in impoverished, drought-stricken communities. Most households in these communities possess no electricity or plumbing, and many women reported walking long distances daily to fetch water and firewood.

Table 2: Respondents demographic information (n=41)

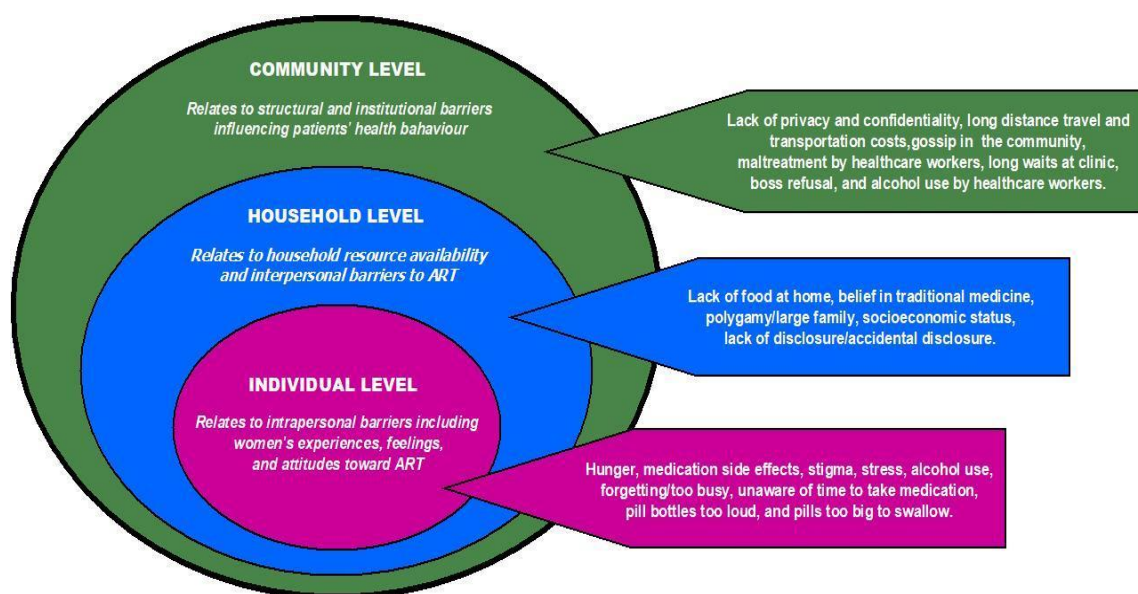
Characteristics	N (%)
Age Mean (SD)	36.31 (7.29)
Education	
Did not attend	7 (17.7)
Primary	16 (39.0)
Secondary	16 (39.0)
Marital Status	
Married	19 (46.3)
Not married	13 (31.7)
Living with partner	2 (4.9)
Divorced/separated	2 (4.9)
Widowed	5 (12.2)
Support	

Family	32 (78.0)
Friends/neighbors	4 (9.8)
No one	5 (12.2)

Rural Swazi households typically depend on subsistence farming for food. Several women in the discussion groups expressed concerns that what used to be land for families to grow food crops is now being used as sugarcane plantations. Households across rural Eswatini have been persuaded by local chiefs to abandon growing staple crops and instead join sugarcane growing cooperatives. The expansion of sugarcane production has had significant implications on food security for local residents. Residents of these communities are being prohibited from growing food crops, and the dividends from the sugarcane cooperative are often insufficient to support families. In FGDs, women frequently commented about whether joining the sugarcane cooperative was worth it, as they have lost all traditional means of food production for their families.

The study findings of emergent themes are presented using a social ecological model to explore and understand the multiple level factors that interact and influence ART adherence (Figure 6).

Figure 6: Summary of Themes Identified Based on the Social Ecological Model



5.3.1 Individual Level Factors

Individual level factors relate to women's experiences, feelings, and attitudes towards ART. Primary factors identified as barriers to ART adherence included: hunger, medication side effects, stress, stigma (both self-stigma and perceived public-stigma), forgetting or being too busy to take pills, being unsure of time to take medication, loud rattling of pills in their bottles, and pill size too big to swallow. Excess alcohol use was identified by healthcare workers as a negative influence on ART adherence.

Hunger

Hunger was often reported by both healthcare workers and study participants, as a significant barrier to ART adherence. Healthcare workers instruct patients that ART medication must be taken with food at all times. A majority of the respondents reported that the main reason they missed doses was lack of food, and that they were afraid of getting sick if they took the medication on an empty stomach. This was particularly challenging for women living in poverty who reported occasionally going several days with insufficient quantities of food to feel safe taking the medication. This issue was even more evident for those who were prescribed dosages twice a day, and resulted in women skipping doses if they did not have enough food to eat or they could not borrow food from their relatives or neighbors.

"You need to eat first. I once fainted when I took the pills without eating. I take it twice a day, morning and evening. Sometimes I skip taking it if I don't have anything to eat." (Participant S)

Healthcare workers reported lack of food as a significant barrier to ART adherence. They pointed out that due to high unemployment rates and five consecutive years of local drought, many of their patients were struggling to make ends meet, with lack of food being a primary concern.

“Most times they complain about lack of food, they say they can’t take the pills when they don’t have anything to eat.” (Healthcare worker M)

Medication side effects

Both healthcare workers and patients identified medication side effects as having a major influence on ART adherence. Side effects reported were: stomach pain, increased appetite, burning in the chest, dizziness, nausea, hallucinations, fatigue, and body deformities. However a majority of these side effects were hunger related, as participants reported worse side effects when medication was taken without food. Some participants reported that medication side effects were so severe that they had difficulty sleeping at night and often struggled to function normally during the day. Such experiences resulted in poor medication adherence by participants, including skipping of doses in order to avoid hunger-related side effects.

“One time I took the pills without food and went to work, I almost died. Yes the pills are a problem if you take them hungry because you get dizzy, and they make you shake and have hallucinations.” (Patient C)

“They complain that the medication makes them sick if they take it when hungry.” (Healthcare worker S)

Stigma

Public stigma (real or perceived) and self-stigma were reported as some of the reasons participants missed treatment dosage, missed clinic visits, or discontinued ARV treatment. Most women had a treatment supporter (presumably an individual who was aware of their HIV status), but many had concerns about disclosing their HIV status to families, communities, or social networks for fear of being scorned or rejected. Some reported having heard negative gossip about individuals receiving ART, and

worried that individuals in their families, communities, and social networks would think less of them if they knew they were taking “bophinduvuke/ bohohlohohlo” (derogatory terms for ARVs), and they would also become the source of gossip.

“I’m afraid because I don’t know what people would say if they knew I’m taking the pills. It’s hard to tell them. Sometimes you tell someone, they laugh at you and go tell their friends.”

(Patient S)

Some women also reported experiencing conflict with spouses/partners after disclosing their positive HIV diagnosis. These encounters with intimate partners have sometimes led to rejection, break-ups, blame and/or verbal abuse, and consequently made it difficult for women experiencing such interpersonal conflict to adhere to treatment and/or honor clinic appointments.

“Another thing is the issue with the husbands. You find that you go get tested and find that you are positive and your husband is not. Once he finds out he’s negative, he comes back and accuses you of sleeping around. They ask too many questions and accuse you of cheating. This is giving us problems because you find that there’s no support and sometimes he tells you that he doesn’t trust you and will never trust you because he doesn’t understand where you got the HIV from because he doesn’t have it.” (Patient G)

Healthcare workers reported that self-stigma and perceived public-stigma was highly prevalent among people living with HIV, which in turn has impacted how services are delivered.

“The self-perceived stigma is so high such that people are even ashamed of being seen anywhere near a hospital vehicle, and they don’t want the hospital car to visit them at their homes. Like the car we’re using for Comm ART, it’s not written ... outside because of that reason.” (Healthcare worker G)

Alcohol

Approximately a third of the women reported that they sometimes forget to take their ARVs due to being too busy, being away from home, stress, alcohol use, or having to attend family or community events (e.g. all-night vigils for local funerals, a traditional mourning practice). A few women reported drinking alcohol as a way to cope with stress and hunger.

“I don’t work either but I run a vegetable stall. Sometimes I walk around looking for avocados like now its avocado season. I may get busy, come home late, and forget to take my pills on time.” (Patient S)

*“ahh mntfwanami (my child) I drink when I’m going through a lot of stress... it helps me relax and not think about my problems too much. It also makes me not feel hungry you know”.
(Patient C)*

Healthcare workers echoed patient’s comments, though they believed that alcohol use was another typical reason patients forget to take their medication. During the discussions, we found that most women were apprehensive about discussing their own alcohol use. They spoke about alcohol use in very general terms, identifying the behavior as a barrier to adherence, but were not willing to disclose their own alcohol consumption practices within the focus group setting. However, during the interviews with healthcare workers, excessive alcohol use emerged as the most frequently cited reason for HIV-infected women missing their ARV doses. Likewise, healthcare workers also identified alcohol use as a barrier to ARV adherence, since patients who drink excessively were more likely to forget taking their daily doses as prescribed. Additionally, healthcare workers perceived that alcohol overuse resulted in missed clinic appointments.

“...alcohol use plays a role. Alcohol makes them forget the dates for clinic appointments. I also think that it makes them forget taking their medication on time at home.” (Healthcare worker S)

Timing of medication

A few women reported taking pills late because they did not have a clock, radio, or cellphone to help them keep track of time. Uncertainty of the time of day was a common reason cited for failing to take daily dosage on time. They reported that repeatedly asking “What time is it?” to their children, family members, or neighbors put added stress on those relationships, increasing the risk of revealing their positive status.

“... if I ask a neighbor what time it is so I can take my pills, the neighbor gets angry and goes around telling people that I keep bothering them about my pills.” (Patient S)

Pill size too big to swallow and make noise

Some participants stated that they had difficulty taking their medication because of the large pill size, particularly those with a morning and evening pill schedule. They reported that even if they took them with plenty of water as per other participant’s suggestion, the pills got stuck in their throats causing gagging and sometimes vomiting.

“My only problem is taking the pill, it’s big, it gets stuck on my throat...it’s very difficult for me.” (Patient C)

A majority of the women complained about the loud rattling of the pills in the containers. They reported that the pill containers are very noisy and make a discernable sound that would be recognized as ARVs. They felt embarrassed by the sound and it made them not want to bring pills along while traveling on crowded buses (the main form of transport). During the FGDs, participants questioned the reason ARVs were packaged in different containers than the usual plastic pill packets used for other

medications, and felt that they would be more comfortable picking up their ARVs from the pharmacy window if the pills were packaged similar to other medications in the clinic.

“...also that the containers make a lot of noise. Sometimes I can’t go to the clinic, so I ask my sister to pick up the pills for me. She says, “hey you know those pills are too loud, when I get off the bus I need to carry my bag with care because they make a lot of noise.” (Patient C)

Healthcare workers reported patients regularly complaining about the sound the pill bottles make.

“...some people still have stigma of being found out that they’re taking ARVs. They don’t want to be seen carrying the pills, they say people can hear them because the pills make noise. They often take them out of the container and put them in the regular plastic packets.” (Healthcare worker M)

Stress

Feelings of stress were described by some of the women as an important constraint on ART adherence. Primary sources of stress included anxiety over food supply and lack of financial resources to provide for their children. They reported sometimes forgetting to take pills due to emotional or stressful life events.

“Problem I encounter is that I am unemployed so sometimes something happens, I have too much stress and forget taking my pills.” (Patient C)

5.3.2 Household Level Factors

Household level factors relate to resource availability in the household and interpersonal barriers including relationships with family members, friends, spouses, and sexual partners. Lack of food at home, low socioeconomic status, and lack of disclosure/accidental disclosure were identified by

participants as barriers to ART adherence at the household level. Health care workers reported similar issues as the women in the focus groups, and also thought patients' belief in traditional medicine and tolerance of polygamous relationships were additional negative influences on ART adherence.

Lack of food at home

Household food insecurity may affect ART adherence through the impact of inadequate dietary intake. Both healthcare workers and the women reported shortage of food within the household as the primary reason individuals default on treatment. In an effort to prolong household food supply for the whole family, some women reported limiting personal meal frequency and reducing portion sizes, sometimes skipping meals entirely for one or more days to ensure that their children had something to eat. Food insufficiency in the household made it difficult for the women to prioritize treatment adherence on a daily basis, particularly those experiencing adverse hunger-related medication side effects.

"The painful thing is that we don't have any food to eat at home. When I take my pills hungry, I get severe headaches and burns in my stomach." (Patient S)

"I think lack of food plays a significant role. This place is so dry; there are no rains so people can't grow crops. They rely on buying food from the store and they don't always have the money to do that. There are also no jobs which makes things very difficult" (Healthcare worker C).

Socioeconomic status

Poverty and unemployment are factors that were commonly reported by the women and healthcare workers as having a critical negative influence on adherence. Patients stated that because they were unemployed, they struggled to provide basic needs (food, clothing, school fees, etc) for their children, often did not have bus fare to attend clinic visits, and found it difficult to have enough food to

eat before taking medication. Women with insufficient financial resources report being faced with difficult choices such as whether to spend what little money they have on food for their children, or to travel to an appointment at the clinic for HIV treatment and care.

“Other problems are lack of money and lack food. Most people say they stopped taking ARVs because they didn’t have money to buy food. They complain that the medication make them sick if they take it hungry.” (Healthcare worker C)

Patients also discussed illiteracy as a barrier to adherence. Those with limited reading ability often experienced difficulty understanding treatment schedules. Some reported missing clinic visits because they couldn’t read and/or were reluctant to ask someone to check the date of their next clinic visit on the ART health card due to fear of disclosure of their HIV status.

“One time I missed the date for clinic visit ...Even now I don’t know when I need to go back because I don’t know how to read, I ask somebody else to check the date for me to see when I’m going back next.” (Patient C)

Lack of Disclosure/Accidental Disclosure

Participants regularly conveyed fear of having their HIV status revealed to family or community members. Though nearly all study participants had disclosed their HIV status to at least one person (typically a close friend or family member), the women were concerned about accidental disclosure of their status to members of their social group and/or communities. Furthermore, women reported fear of being seen near the mobile clinic during Comm ART visits, and worried about being recognized at the clinic’s ART unit, when picking up meds or attending appointments. Some even opted to travel to more distant clinics to avoid being seen by people they know at the facility. A few reported that they hid from

expert clients/healthcare workers conducting follow up visits if the workers arrived in marked clinic vehicles due to the shame and fear of their HIV status being revealed to their neighbors or family.

“Even though refills are done at..., I like coming here to ... because nobody can see me. Even though I accepted my situation, I don’t want other people to know because people talk.” (Patient S)

Healthcare workers corroborated the above comments, adding that they suspect the reported level of HIV status disclosure may be overestimated. They reported finding that often patients would provide false contact details regarding their treatment supporters. It was suspected that many patients likely had not disclosed their HIV status to anyone.

“And you find that when we call the number they gave us, the person on the phone either doesn’t know the client or they are not aware that they’ve been registered as the patient’s treatment supporter. Sometimes it’s very difficult to reach them, especially those who haven’t disclosed...they run away and hide from us... they don’t like home visits.” (Healthcare worker S)

Polygamy and large families

Polygamy was believed by healthcare workers to negatively affect adherence. Most households serviced by the clinics exist in a state of permanent extreme poverty. In a polygamous household, scarce funds must be allocated by the head of household among multiple wives, which can in turn be difficult for HIV-infected wives within the household to secure adequate funds for treatment-related costs (i.e. transportation to the clinic). This is especially difficult for those who have not disclosed their HIV status, as they must stretch their budget to also include treatment-related costs. Wives who have disclosed their HIV status face an increased risk of being rejected, and ostracized by family members and the other wives. Additionally, wives in polygamous households who had disclosed their HIV status to

husbands reported fearing their husbands revealing their illness to co-spouses who would then judge and blame them for bringing disease into their families. Healthcare workers reported that many patients in polygamous/ large families choose not to reveal their HIV status to anyone, making it difficult for them to take their medications consistently.

“I think living in big families does play a role. Sometimes wives are afraid to tell their husbands because they worry that if they tell them the husband will tell the other wives and everybody will blame her for bringing HIV to the family.” (Healthcare worker C)

Beliefs in traditional medicine

Although the use of traditional (indigenous or ancestral) medicine was not discussed extensively in the focus groups, some women did report that they alternate between ART and traditional medicine, while others reported stopping treatment entirely in favor of traditional medicine. Healthcare workers identified traditional medicine as a contributing factor to ART nonadherence.

“To add on the cultural traditions, some people still believe in traditional medicine. They tend to either not take the ARVs because they believe the traditional concoctions will cure them or they mix the meds with these concoctions. Either ways this affects adherence.” (Healthcare worker G)

5.3.3 Community Level Factors

For this study, community level factors refer to the structural and institutional barriers that influence women’s health behavior. Some of the barriers to ART adherence commonly reported by participants included lack of privacy at the clinic, travel time and transportation costs, gossip in the community, maltreatment by health workers, and excessively long waits at clinics. An unexpected but commonly reported barrier regarded local employers not allowing workers to take time off for clinic visits. Health workers reported that excessive alcohol use among co-workers while on duty was having a negative influence on patient’s ART adherence.

Lack of privacy and confidentiality

Lack of privacy and confidentiality at the hospital was reported as a major barrier to adherence by both the women and healthcare workers. Some patients complained that local healthcare workers lacked confidentiality as they would sometimes gossip or discuss patients' HIV status with other community members. The women also expressed anxiety regarding the separate and distinct location of ART Units within the clinics. They spoke of feeling uncomfortable being seen while picking up easily identified ART pill bottles from the pharmacy window. They also complained about having to hold their distinctly colored HIV Care files while queuing (usually in open spaces) for appointments or moving around the clinic, which compounded concern of being identified by family and/or members of their community. It was reported that for some patients the lack of privacy and risk of exposure was so unbearable that they stopped going to the clinic entirely.

"Problems we encounter are problems at the hospital. Because sometimes you get scared to go pick the medication, because when you get there sometimes, they give you the green files to hold while waiting and everybody can see. Even people who are passing by they can see that these people have HIV. They make us sit outside with our files. And they also make us take the medication from the pharmacy window where everybody can see." (Patient M)

"Another issue is that in some clinics, ART people are made to que in a separate line which makes some people uncomfortable. Especially those who haven't disclosed their status, they don't want to be seen standing in line for HIV positive people." (Healthcare worker G)

Long distance travel and transportation costs

Transportation costs and travel distance were reported by the women and healthcare workers as contributing factors to nonadherence. Even with free ART and increased availability of HIV care services in remote health facilities, most individuals seeking treatment had to travel to centrally located

clinics for their monthly ART refills. For women living in remote rural villages, just getting to the clinic to pick up monthly prescriptions may pose a significant challenge, and can often take an entire day. Unemployed women with limited financial resources reported that often bus fare was unaffordable. Many were forced to walk long distances of approximately 10 miles to and from the clinic. These women reported that if they did not show up early enough to the clinic, they risked not being seen that day and would have to repeat the travel process at a rescheduled appointment. Some described having to wake before dawn and walk several hours in order to arrive at the clinic by 8am. These financial and geographic challenges to health care access lead to missed clinic appointments and poor adherence to ART.

“It’s too far, like me I get them from To get them, I need to have bus fare. If I don’t have money, I walk through the cane fields, it’s too far, by the time I get back my feet hurt... then I need to come back and work here at home.” (Patient C)

“Yes, lack of money for transport makes them skip clinic visits. Some live in areas where there’s no public transport they walk long distances through mountains to get to the clinic.” (Healthcare worker M)

Gossip in the community

Despite significant progress being made raising HIV awareness in Eswatini, patients reported fear of being scorned and gossiped about by community members if their HIV status is discovered.

“You also find that you’re worried that if you tell people you live with about your situation, they will go around telling everybody in the community. That’s another problem that even if I go get the pills at the clinic, when people see me, they will laugh at me that I’m taking these pills. They gossip about people in the community.” (Patient S)

Healthcare workers echoed patient's concerns and acknowledged gossip was still widespread in the communities that the clinics served. They reported that due to fear of being the subject of gossip, patients would often avoid Comm ART services, fail to attend clinic appointments, skip doses, and neglect refills.

"...people gossip about them, they say all kinds of negative things about people taking ARVS.

They even use derogatory terms like "phinduvuke (rose from the dead), hohlohohlo (rattle sound made by ARVs pill bottles)". (Healthcare worker G)

Maltreatment by healthcare workers

The women reported being treated poorly by clinic staff, describing that they would get yelled at or punished if they arrived at the clinic late (after 11am) or missed an appointment. Furthermore, the women stated legitimate excuses for missed appointments were never accepted, and when they did attend the clinic at a later time, healthcare workers would humiliate them and make them wait outside until everyone else had been helped.

"They don't understand, they yell. One time I missed the date for clinic visit and they made me sit outside for hours. I was so hungry and I had no money to buy food. I thought of leaving but I couldn't because I knew I was going to go through the same thing if I left. "(Patient C)

Women also described being reprimanded at pill counts if they had the incorrect number of pills left. As a consequence, they reported throwing away excess pills prior to counts, to ensure that they would not be treated poorly. Some clinics report high adherence rates, yet staff interviewed indicated their suspicion that these numbers may be grossly inaccurate.

“But you find that sometimes patients would show a 100% adherence but when you look at them, they look so sick. Then you wonder what they do with pills, sometimes I think they throw them away.” (Healthcare worker C)

Healthcare workers acknowledged that there were problems with the way patients were treated by clinic staff. Those interviewed stated that healthcare workers often yelled at patients, using derogatory terms such as “laba babo ART” (those for ART) when referring to patients receiving treatment.

“...poor service at the clinic might be driving some people away. When they come here looking for help and they’re not treated well by the staff, they go away and don’t come back, sometimes for months on end. Sometimes they get yelled at when they arrive at the clinic late. Yet there are things that make them get to the clinic late, things like the issues of disclosure and long distance travel.” (Healthcare worker S)

Long waiting time

The women reported having to wait long hours for service at the clinics. Some reported waiting up to six hours before receiving care. At times, the wait was so long that the clinic closed (at 4pm), and they were forced to leave without medication refills. Women reported frustration over the waiting times in the clinic. The wait is particularly difficult for employed individuals, risking losing wages and even sometimes their jobs. Long wait times were also identified by both healthcare workers and the women as a major problem, particularly for people rushing to go back to work and those living in remote areas. Healthcare workers pointed to understaffing issues as being the source of the problem.

“Even at 4 when they close. They leave you like that. Even if you can wake up early...like at the firm you ask permission from the boss thinking that you’ll get helped early but no. Then you miss work, and they don’t give you a sick note...then it’s a problem now.” (Patient M)

“Some people complain about the waiting at the clinic. We are understaffed here so sometimes it takes a long time to help everybody.” (Healthcare worker S)

Employer refusal

Most of the employed women reported that they did not disclose their HIV status to their employers and co-workers. Several women talked about occasionally missing clinic appointments or failing to refill medication due to a boss/supervisor at work refusing to give them time off. When they ask to attend a clinic appointment, supervisors demand a reason for going, which resulted in fear of disclosing status and being overheard requesting to pick up HIV medication. Some of the women also experienced threats of job termination by their boss/supervisor when they requested time off to attend a clinic appointment.

“Like they’ve said it’s a problem at work. When I asked to come to the clinic from my boss, he told me to leave and never come back. I told him that the reason I asked is because I needed to pick up my pills. He refused and said if I leave I leave for good. I stayed....” (Patient S)

“But another big problem here atare the firms, their bosses don’t want them to take a day off to come pick-up their meds every month, even if we give them a sick note.” (Healthcare worker M)

Alcohol use by healthcare workers

Clinic staff (particularly Expert Clients) are employed with the expectation that they will be good counselors and role models for people living with HIV. In spite of this, during interviews, healthcare

workers identified excessive alcohol consumption by co-workers while on duty as a major barrier to ART adherence. They described some co-workers arriving at work at 8am already intoxicated, while others would consume alcohol during lunch breaks. They believed that co-workers' alcohol consumption negatively impacted service delivery and was affecting ART adherence. Since alcohol consumption is known to negatively affect medication adherence, healthcare workers felt that these co-workers were presenting a poor role model for patients.

“When it comes to alcohol use it’s a very difficult situation, particularly because even the health workers themselves, the people you expect to counsel them against drinking and to lead by example, are drunkards themselves. We try to educate people about the effects of alcohol on the medication...we tell them to not drink alcohol because it makes the medication not work properly, but how can you expect them to take us seriously when some health workers are doing the same. Health workers should lead by example.” (Healthcare worker G)

5.4 Discussion

This study uses the social ecological model (SEM) as an organizing and analytical framework to identify and understand the dynamic interplay between multilevel risk factors that influence adherence to ART among rural women in Eswatini. Our findings reveal that adherence to ART is a complex behavior that is heavily influenced by barriers that operate at the individual, household, and community/institutional levels. For example, household food insecurity, particularly at the level of hunger, directly affected ART regimens due to women's experiences of adverse side effects when the medication was taken on an empty stomach. Behaviorally, women reported skipping ART doses when the quantity of food within their home was severely limited. Several studies in the region have reported similar findings, and in some cases, individuals stopping treatment completely due to anxiety over side

effects from ART medication when access to food was compromised and inadequate (12–14). In addition, healthcare workers cited hunger as one of the key reasons for missed doses.

Food and nutrients play a significant role in the metabolism of drugs and their distribution in the body, and food scarcity may lead to an increased risk of side effects from anti-retroviral treatments, making it difficult for women with inadequate dietary intake to adhere to medication(91). In Swazi households, women are traditionally responsible for ensuring that children and other family members are adequately fed. For women living in poverty, this presents an ongoing challenge. As a coping strategy, women from food insecure households reported reducing meal frequency and portion sizes for themselves in an effort to prolong the household's food supply. This finding is similar to a Zambian study that also reported a lack of food within the home as being a significant reason for defaulting on treatment(12). Furthermore, hunger and food insecurity were identified as major factors in recent qualitative and quantitative studies investigating barriers to ART among countries in sub-Saharan Africa(11,38,62,92–94).

Intervention studies providing food supplements and nutritional support have been shown to improve ART adherence(35,95). In a recent World Food Program (WFP) report of the Food by Prescription program in Eswatini, food supplementation was shown to significantly improve ART adherence(80). In collaboration with local health facilities, WFP provided food assistance to approximately 2,400 patients from 2012-2017, an intervention that illustrated that nutritional support was associated with a 16% increase in ART adherence rates among beneficiaries. Overall, these studies suggest that improving food security facilitates adherence and access to ART thereby improving health outcomes.

The communities covered in our study suffer from widespread poverty exacerbated by drought, and during the timeframe of our study, received no nutritional support from NGOs or government programs. Traditionally in rural Eswatini, when shortages are experienced, sharing food reserves with

neighbors who request aid is culturally expected, and the women in our study commonly reported borrowing food from neighbors. However, this traditional practice was reported by the women as resulting in increased tensions and worsened relationships with neighbors when food was not reimbursed as promised. Fearing condemnation and refusal of future assistance, women must try to repay neighbors the borrowed food while trying to find food for their own family, causing stress for the women who owe food.

Lack of food and resulting hunger were not the only sources of stress in the women's lives. Lack of financial resources was an overriding stressor for the women, with little indication of resolution due to high unemployment rates particularly for women in rural settings. Women living in this state of recurrent poverty often reported having to spend any available funds on household necessities (food and farming supplies) instead of seeking HIV treatment and care. While the Swazi government provides free ART treatment for all HIV positive people in the country, individuals living in remote areas often travel to the clinic using public transportation and must pay for transportation out-of-pocket as these costs are not covered by the free government programs. In this study, women reported feeling stressed when they did not have money to cover transportation costs, buy food, and/or to pay for their children's school fees and educational needs. Poverty and food insufficiency not only cause stress among individuals, but may also result in a shift away from focusing on long-term health care and instead spending income on necessities to ensure a stable household food supply(96). A recent study of HIV positive adults in Lesotho identified stress as a major barrier to ART adherence(93).

In our study, women reported excess alcohol use as a common strategy for coping with stress and hunger. Alcohol has been documented as a widely used means of coping with a range of stressors including economic stress, job stress, marital problems, and lack of social support; and evidence indicates that the more severe and chronic the stressor, the greater the alcohol consumption(97–99). In Eswatini, 59% of those who drink regularly consume a homemade traditional brew, commonly known as

umcombotsi(100). Prepared by females and served at local drinking spots (*shebeens*) throughout Eswatini, the drink is inexpensive (approximately \$0.25 USD per liter) and easily accessible to community members. The *umcombotsi* can be purchased with cash or by bartering services or goods (food, household items, providing labor, etc.). Alcohol use was cited by healthcare workers as one of the main reasons that patients missed appointments or forgot to take their medication. High levels of stress combined with easily available alcohol create enormous problems in communities already burdened by poverty and disease.

Alcohol use has been identified by both patients and healthcare workers as a contributing factor to ART nonadherence among countries in southern Africa(12,62). In a qualitative study of HIV positive adults in South Africa, patients confessed to discontinuing treatment once they started drinking alcohol(62). While women were apprehensive about discussing their own alcohol use in our study, alcohol use was often cited by healthcare workers as a typical reason patients missed appointments and missed doses. Parallel findings were reported in a study investigating barriers and facilitators of ART adherence among HIV positive patients in Lesotho(93).

A surprising revelation from healthcare workers identified excessive alcohol consumption by co-workers while on duty as a major barrier to patients' ART adherence. Alcohol use by healthcare workers could have both acute and long-term consequences for staff-patient interaction in the workplace. In our study, healthcare workers reported excessive alcohol use by co-workers as having a negative effect on staff conduct and service provision. According to healthcare workers, co-workers who drink were likely to be impatient, dismissive, and often displayed a negative attitude toward patients, which led to patients' maltreatment and poor service delivery. Excessive alcohol use and/or hangover effects may lead to inefficiency, poor judgement, and absence from work, all of which may negatively impact ART adherence(101).

Identifying structural and institutional barriers that influence women's health behavior was also accomplished by using the SEM model. Patients reported that confidentiality issues and a general lack of privacy had a significant influence on their ART adherence. They were worried that sitting at clinics in highly visible designated HIV patient waiting areas, picking up easily distinguishable HIV treatment pill bottles from the pharmacy window, and holding their uniquely colored HIV care files while queuing put them at risk for accidental disclosure of HIV status. Some patients complained that local healthcare workers displayed a lack of confidentiality, sometimes gossiping or discussing patients' HIV status with other community members. Other studies have reported lack of confidentiality as a major reason patients missed clinic appointments and discontinued accessing ART from local clinics(44,102,103). In our study, women expressed concerns about the location of the ART units and/or pill counting stations at the clinics, and feared that they would be seen by people they know while queuing for service during clinic visits. The fear was so intense that some women completely avoided utilizing local services, instead opting to attend more distant clinics for ART. In a recent study conducted among caregivers of HIV positive children in Eswatini, researchers reported that in an effort to gain privacy, patients routinely switched clinics, which led to treatment interruptions and missed clinic appointments(44).

Gossip at the individual-, household-, and community level is rampant among rural communities of Eswatini, and being the subject of gossip is regarded as an egregious insult to one's character. The SEM was instrumental in helping us identify the effects of gossip across multiple levels, and elucidate important information to help us understand health behaviors as determined by a set of interconnected individual and contextual factors. In our study, patients worried that if people became aware of their HIV status, they would become the subject of gossip among family and community members. For women in polygamous marriages this was particularly challenging. In addition to concerns over gossip, they feared being blamed, rejected, and ostracized by their husbands and co-spouses if it was discovered that they were HIV positive. This behavior can make it harder for people living with HIV to

feel accepted. The concern patients have of being “found out and gossiped about” creates barriers to accessing and utilizing local ART services and affects ART adherence.

Stigma (both self-stigma and public stigma) at the individual-, household-, and community level were often cited as contributors to nonadherence, as patients reported fear of being judged and shunned by people in their families, communities, and social networks if they were known to be using ARVs. Healthcare workers reported that while patients might reveal HIV status to their partner or close household members, they were unlikely to tell friends or extended family members. Various studies have identified fear of accidental disclosure and stigma as significant factors affecting ART adherence(41,62,103). In a recent study of HIV positive pregnant women in Eswatini, Fay et al. (2015) examined and described factors influencing ART adherence and found that self-perceived stigma and lack of disclosure were often reported as contributors to poor ART adherence. In a study investigating barriers to ART adherence in Western Cape in South Africa, fear of unintended disclosure and stigma were reported as the main reason patients discontinued accessing ART from clinics(62).

At the community level, longer travel distances, increased travel time, and fewer transportation options available in the rural communities were issues reported by both patients and healthcare workers as hindering ART adherence. The influence of community characteristics, independent of individual and household factors, has been known to exist across a range of public health outcomes, including chronic diseases, health perceptions and behaviors, and women’s health(55,56,58,104). Patients reported spending up to 6 hours traveling to and from the clinic just for medication refills. This was particularly challenging for patients with limited financial resources as they often did not have funds for transport.

For women not enrolled on Comm ART, this posed additional difficulties as they were required to travel (often long distances) to health facilities to pick up monthly medication refills. For those living in remote villages, simply picking up monthly prescriptions might take an entire day. If employed,

patients must take the day off, risking loss of employment. If unemployed and they cannot afford to pay for transportation, patients must walk to the clinic, commonly walking distances greater than 10 miles (16 kilometers) round trip. The cost of both transportation and time spent traveling is substantial for rural woman, and competes with other basic and essential expenses such as food, shelter, and education (school fees and uniforms for their children). Travel difficulties led to patients arriving late or missing appointments, which then often led to punishment and maltreatment by clinic staff. In resource limited settings, long travel distance to health facilities and transportation costs were commonly cited as barriers to ART adherence(12,44,62). Increased distance to one's health care facility has been associated with poor health care access and negative health outcomes(60).

Several women reported that they would occasionally miss a clinic appointment or fail to pick up medication because their boss/supervisor would not let them leave work. This created difficulties because patients who had jobs typically worked six days per week during the same hours that the clinic was open. Missing a clinic appointment for any reason was often met with punishment by clinic staff, with women reporting being yelled at and forced to wait unusually long hours for service. A few patients described being made to wait outside until the clinic closed, then being sent home without receiving a check-up. Pill counts are part of every check-up and many patients reported that if they arrived at the pill count station with too many pills, they would get yelled at. As a result, patients resorted to discarding excess pills prior to counts, skewing reported adherence rates. In a study investigating patients' attitudes toward decentralization of HIV care in South Africa, fear of maltreatment by staff was reported as a major concern among patients accessing ART from local clinics(103). Poor treatment by healthcare workers, being yelled at, and unnecessarily long wait times may discourage patients from returning to the clinic for their refills and may lead to patients being lost to follow-up and defaulting treatment(44,102).

A few women had issues with the ART pills being large and hard to swallow. A more common concern was the loud sound that the pills made in the containers. Due to the widespread nature of the HIV epidemic in Eswatini, the ART medication bottles (and the unique sound that the bottle makes when rattled) are easily recognizable by nearly everyone. Women feel embarrassed by the sound and worry about bringing pills along while traveling or attending family and community events. Some women reported friends or relatives refusing to pick up pills from the clinic for them because they did not want to be seen or heard carrying ARVs.

Strengths

To our knowledge this is the first qualitative study to investigate barriers to ART adherence among rural women in Eswatini (one of the most vulnerable populations for HIV). Study findings provide detailed information regarding the complex behavioral influences of ART adherence. As far as we know, our study is the only study to reveal additional barriers such as gossip and alcohol use by clinic staff that has not been reported in previous studies. By describing multi-level factors that exert an influence on patients' ability to access and utilize ART, we were able to comprehend and contextualize the difficulties that women face regarding treatment. This study utilized a data triangulation approach (concurrently gathering data from patients and healthcare workers) which helped strengthen the authenticity of the reported themes and provided comprehensive understanding of the factors influencing ART adherence in a rural setting. The study employs a social ecological model to investigate individual, household, and community/institutional barriers to ART adherence and further explains how barriers across multiple levels interact and influence ART adherence. In addition to helping to clarify these factors, the model also suggests that in order to improve ART adherence, it is necessary to act across multiple levels of the model at the same time. This information may help inform policies and potentially assist in designing and implementing support programs aimed at increasing ART adherence in Eswatini.

Limitations

The purposeful sampling method used to recruit participants into the study may be limited by a level of selection bias, given that focus groups were comprised of women living with HIV who chose to participate, not all infected women approached participated in the study. It was especially difficult to reach women completely defaulting on treatment, as those women were actively avoiding contact with health workers.

As with all qualitative research, the role of the moderator or interviewer could potentially be a source of bias. In order to mitigate potential moderator or interviewer bias, all interviews and focus group discussions were moderated by the PI (trained in qualitative research methods and conducting interviews). While focus groups are useful for understanding experiences and attitudes of a group or personal health behaviors, an inevitable amount of bias could occur through group dynamics. Participants may be reluctant to voice opposing views, or the more assertive participants may disproportionately influence reported themes. However, we believe peer influence was minimal as all participants were encouraged to share their honest opinions and were given an opportunity to discuss their experiences or feelings toward ART freely. Despite the limitations, this study provides a better understanding of the individual, social, and structural barriers influencing ART adherence among women in rural Eswatini.

5.5 Conclusions and Recommendations for Practice

Treatments for HIV can improve immune functionality and decrease morbidity and mortality, offering hope that HIV/AIDS can be more effectively managed. Optimal level of adherence to ART is crucial for achieving and maintaining a suppressed viral load for HIV infected individuals. However, lapses in ART adherence may render these complex treatment regimens ineffective. Applying a social ecological framework to investigating the multilevel risk factors to ART adherence elucidated valuable

insights into the challenges faced by women in rural communities of Eswatini. Hunger related side effects from ART medications, poverty, and food insecurity emerged as critical barriers to ART adherence. Findings from this and other studies strongly suggest that the implementation of sustainable nutritional and food security interventions integrated with HIV/AIDS programming would substantially improve effectiveness of ART treatment.

During our discussions, women were asked what strategies they thought would help improve ART adherence. Some common suggestions included: improving service delivery at clinics, enabling Comm ART services to all patients, providing food/nutritional supplements, enacting policies to deal with gossip and stigma in communities, and help with transportation costs. Most women also voiced concerns regarding gossip and exposure of HIV status due to issues such as: lack of privacy at ART units in clinics, everyone having to carry around their green folder essentially declaring HIV status to all nearby, unprofessional conduct by healthcare workers, and the widely recognized rattling sound made by ARV pill containers. Changes could be made to the location of ART units with an emphasis placed on privacy and confidentiality. Patients should not have to carry folders which reveal HIV status. Pill containers should be altered to reduce noise. Healthcare workers should be retrained to be more compassionate and understanding of the challenges faced by HIV patients.

Comm ART should be expanded to additional communities and made accessible to patients of all levels of adherence. Transportation costs need to be addressed. No one should be denied access to medication or have to miss appointments simply because they cannot afford bus fare to the nearest clinic. The poorest and most vulnerable HIV patients in Eswatini face daily challenges that significantly impact ART adherence. Initiatives aimed at reducing their financial burden regarding HIV treatment would be most beneficial. ART adherence must be prioritized for Eswatini to achieve its goal of eradicating new infections and ending AIDS by 2022.

CHAPTER 6

MANUSCRIPT 2

“I DIDN’T TAKE THEM (ARVS), I HAD NOTHING TO EAT.” FINDINGS FROM A MIXED-METHODS STUDY INVESTIGATING BARRIERS TO ART ADHERENCE AMONG WOMEN FROM RURAL COMMUNITIES OF ESWATINI

6.1 Introduction

Retention in care of patients undergoing Antiretroviral Therapy (ART) is essential to decreasing HIV transmission and improving quality of life for those infected with the virus. Optimal adherence to ART is associated with: increased CD4 cell counts (a measure of a healthier and stronger immune status), decreased risk of HIV transmission, sustained HIV suppression, and improved overall health(31,105) . Poor adherence to HIV treatment is associated with reduced efficiency of viral suppression, increased risk of opportunistic infections, and increased risk of mortality(34,106). Effective use of antiretroviral treatment requires more than just taking medication. It calls for routine monitoring of patients and constant adherence to medication in order to ensure optimal viral suppression and prevent HIV transmission. Despite substantial progress toward making HIV medication available and affordable for those living with HIV in Eswatini, adherence to ART regimen continues to be a significant challenge among HIV-infected individuals. According to a report by the Eswatini Ministry of Health, lack of compliance to HIV treatment and care is one of the primary challenges facing HIV programs in Eswatini(77), yet there is limited scientific data regarding ART adherence and its associated factors.

Since the first case of AIDS was reported in Eswatini in 1986, the virus has spread at an alarming rate. Currently 27.2% of the adult population lives with HIV(3). Over the past decade, the Ministry of Health (collaborating with non-governmental organizations (NGOs) and the private sector) initiated strategies to increase ART coverage and decentralization of HIV care services to lower level health

facilities, particularly those in rural areas. Through rapid response in implementing targeted interventions including HIV testing and counselling, prevention of mother-to-child transmission, voluntary male circumcision, and increasing ART provision and services across the country, Eswatini has made significant progress in preventing new infections and ensuring treatment access to all infected individuals. Unfortunately, insufficient progress regarding the upward trajectory of HIV prevalence has been observed thus far.

In 2016, an estimated 231,609 people were living with HIV, and approximately 180,248 were receiving antiretroviral treatment(9). An estimated 8,800 people were newly infected with HIV in 2016, and among these, 53% were women(19). This has been particularly challenging for the healthcare sector in Eswatini, which is currently overburdened with an increased prevalence of illnesses associated with AIDS, with approximately 3900 people dying from AIDS related illnesses in 2016. When taken consistently as prescribed, antiretroviral therapy has been shown to reduce morbidity and mortality among those living with HIV(107,108). Therefore, the above statistics are disconcerting as they suggest that either HIV infected individuals delay starting treatment and/or are not adhering to ART medications.

Beyond the healthcare sector, HIV/AIDS has and continues to threaten the stability of families and communities in Eswatini(109). As more people succumb to the pandemic, a vicious cycle is created. Reduction of family incomes due to morbidity, and increased expenditures on health care and funerals, cause a decline in personal savings and investments(109). For unemployed women this is extremely challenging, as the deaths of spouses/partners often leave them without means to provide for themselves and their families. In Eswatini, women typically run the household, taking on the role of primary care givers, and often the most significant providers of emotional and physical support for HIV-infected family members. Women with HIV who manage single-parent households may carry additional

burden managing their own health, while providing care and support for their families, often under impoverished circumstances.

Despite the high prevalence of HIV, stigma is a significant concern for infected individuals. For rural women living with HIV this is particularly challenging, as they are often stigmatized as immoral and ostracized by family members if their HIV status is discovered (23,29). The fallout from the stigma surrounding HIV disrupts family dynamics, strains relationships, and negatively affects children.

HIV/AIDS remain a major public health and socio-economic challenge for Eswatini as many families across the nation suffer from limited access to resources including basic needs such as food and clean water. Approximately 69% of the Swazi population live below the poverty line, among which, 80% reside in rural areas(8). Current estimates indicate that 71% of Eswatini households are food insecure. Within this context of extreme food insecurity are over one hundred thousand women receiving ART treatment(9,10). A growing body of evidence indicates that food insecurity increases the risk of HIV transmission, ART nonadherence, and may lead to negative clinical outcomes (increased HIV replication, heightened disease progression, reduced viral load suppression, and increased morbidity) among people living with HIV/AIDS(11–15). Household food insecurity, a state of inadequate access to food of sufficient quantity and quality or the inability to acquire food in socially acceptable ways(11,49,110), has been identified as a major barrier to ART adherence. Previous studies that examined this barrier were primarily conducted in urban settings, none were in Eswatini. This study examines food insecurity among a group particularly vulnerable to HIV-infections and domestic abuse, rural Swazi women, who additionally face cultural norms that inherently oppress women(25,27).

Poverty has been reported as one of the primary factors behind the high rates of HIV transmission among women in Eswatini(109). Poor women with limited opportunities often resort to transactional sex to financially support themselves and their children. In a recent qualitative study of sex workers living with HIV in Eswatini, it was reported that women often resorted to sex work as a way

to make money to buy food. In the same report, participants reported difficulty taking HIV medications when there was insufficient food in the household(29). A study conducted by Weiser et al. (2007) among women in Eswatini and Botswana determined that food insecurity was associated with increased intergenerational sex, and sex exchange for food and money along with inconsistent condom use, all of which increases the risk of HIV infection among women(26). An increase in risky sexual practices as a consequence of food insecurity can also act as a significant barrier to ART adherence(15,26,29).

In 2015, Eswatini implemented a Test and Start program aimed at increasing HIV testing and ART initiation immediately after an individual has been diagnosed with HIV. The program greatly facilitated scaling up of ART programs and consequently helped reach thousands of people living with HIV/AIDS. While intervention strategies have been adopted by the Swazi government and private organizations to help combat the spread HIV/AIDS and its associated consequences, lack of compliance to treatment continues to be a significant challenge for HIV programs throughout the country. Currently, the percentage of patients remaining on treatment after ART initiation decrease over time (i.e. as duration on ART increases, ART retention rates decreases)(90). This is a major concern to ART programs as it suggests that patients are being lost to follow-up, and likely not adhering to treatment. For HIV/AIDS programs to be successful in ensuring treatment adherence and patients' retention to care, it is critical to investigate and identify factors that may facilitate or inhibit patients' access and utilization of treatment.

Therefore, the purpose of this study is to identify factors associated with ART adherence among women in rural Eswatini. To our knowledge this is the first study that uses mixed methods to investigate multilevel influences on ART adherence of rural women living with HIV, who are particularly vulnerable to the wide-reaching impact of extreme poverty. By revealing individual, social-cultural, and structural barriers to ART adherence for economically vulnerable women, the study generates information that may help inform targeted interventions aimed at improving ART adherence among women in rural

communities of Eswatini. Additionally, using mixed methods enabled us to explore the phenomenon of adherence to ART among rural women in a comprehensive manner and helped provide rich contextual data for interpretation of quantitative findings. By using a sequential exploratory design, we were able to: 1) explore and understand complex behavioral dynamics influencing decision making for rural women, 2) identify the difficulties that rural women living with HIV face regarding treatment, and 3) determine the extent to which different factors operating at multiple levels interact and influence ART adherence.

6.2 Methods

See Chapter 4 for detailed information on the study methods.

6.3 Results

6.3.1 Qualitative Results

Table 3 presents barriers of ART adherence as reported by study participants and healthcare workers. In this section, barriers that were found to be significant in quantitative data analysis and frequently identified as major barriers from qualitative findings are presented. Comprehensive findings of the barriers to ART are reported in our previous publication.

Hunger

Hunger was repeatedly reported by both healthcare workers and study participants, as a significant barrier to ART adherence. Healthcare workers instruct patients to take ART medication with food at all times. However, a majority of study participants reported missed ART doses was due primarily to a lack of food, and a concomitant fear of unpleasant side-effects of taking ART medication on an empty stomach. This was particularly challenging for women living in poverty who reported episodic periods of going several days with insufficient food within their household to feel safe taking

the medication. Skipping medication was even more evident for women prescribed dosages twice a day, particularly in situations where the option to borrow food from relatives or neighbors was not available.

Healthcare workers reported lack of food was driven by high unemployment rates and five consecutive years of drought throughout the country, consequently they observed many of their patients struggle to make ends meet, with lack of food being a primary concern.

Medication side effects

Side effects associated with ARVs were identified by both the women and healthcare workers as having a major influence on ART adherence. Reported side effects include: stomach pain, increased appetite, burning in the chest, dizziness, nausea, hallucinations, fatigue, and body deformities. Participants reported worsening of side effects when medication was taken without food. In some cases the severity of the side effects resulted in sleep disturbances/insomnia with notable difficulty functioning throughout the following day. Such experiences reinforced behaviors resulting to poor ART adherence.

Forgetting or being too busy to take pills

Approximately a third of the women reported additional barriers to ART adherence, including : being too busy, being away from home, stress, alcohol use, or having to attend family or community events (e.g. all-night vigils for local funerals, a traditional mourning practice). Healthcare workers were in agreement with the list of barriers, though they believed that excess alcohol intake was a critical problem in the community and contributed considerably to non-adherence to ART. Only a few women reported drinking alcohol as a way to cope with stress and hunger, which in turn negatively affected adherence to their medication.

Stress

Emotional or stressful life events led some women to forget taking their ARV regimen. Most commonly cited sources of stress included anxiety over food supply and lack of financial resources to provide for their children.

Gossip in the community

Despite significant progress in raising HIV awareness within Eswatini, the women reported a fear of being scorned and being the source of 'gossip' in their community should their HIV status be revealed. Healthcare workers echoed patient's concerns and acknowledged gossip was widespread in the communities that the clinics served. They reported fear of being the subject of gossip often led patients to avoid Comm ART services, fail to attend clinic appointments, skip doses, and neglect picking up of ARV refills.

Poor community support services

NGO and government sponsored community-based organizations such as RHMs (Rural Health Motivators) and support groups were put in place to provide assistance for underserved patients in remote areas. Several women in this study reported encountering insufficient support from these local community programs. Common concerns expressed included: lack of consistent availability of key resources (e.g. medication), and support not equally provided to all those who request it. When resources were available, representatives of these organizations were known to display preferential treatment toward friends and relatives.

Long distance travel and transportation costs

Transportation costs and travel distance were reported by the women and healthcare workers as contributing factors to nonadherence. Even with free ART and increased availability of HIV care services in remote health facilities, most individuals seeking treatment have to travel to centrally located clinics for their monthly ART refills. For women living in remote rural villages, just getting to the clinic to

pick up monthly prescriptions may pose a significant challenge, and can often take an entire day.

Unemployed women with limited financial resources reported that often bus fare was unaffordable.

Many are forced to walk long distances of approximately 10 miles to and from the clinic. These women reported that if they did not show up early enough to the clinic, they risked not being seen that day and would have to repeat the travel process at a rescheduled appointment. Some described having to wake before dawn and walk several hours in order to arrive at the clinic by 8am. These financial and geographic challenges to health care access led to missed clinic appointments and consequential poor adherence to ART.

Maltreatment by healthcare workers

The women reported being treated poorly by clinic staff, describing that they would get yelled at or punished if they arrived at the clinic late (after 11am) or missed an appointment. Furthermore, the women stated legitimate excuses for missed appointments were never accepted, and when they did attend the clinic at a later time, healthcare workers would humiliate them and make them wait outside until everyone else had been helped. Women also described being openly reprimanded at pill counts if they had the incorrect number of pills left. As a consequence, they reported throwing away excess pills prior to counts, to ensure that they would not be treated poorly. Some clinics report high adherence rates, yet staff interviewed indicated their suspicion that these numbers may be grossly inaccurate. Healthcare workers acknowledged that there were problems with the way patients were treated by clinic staff. Those interviewed confirmed that healthcare workers often shouted/yelled at patients, using derogatory terms such as “laba babo ART” (those for ART) when referring to patients receiving treatment.

Table 3: Barriers of ART adherence reported by study participants and healthcare workers

Identified Themes	Study Participants' Voices	
	Women	Healthcare workers
Hunger	<i>"I can't take the pills without food in my stomach. Sometimes you find that there is no food at all, I don't take them. How would you take them..." (Participant S)</i>	<i>"Yes, women have been reporting lack of food as a reason they don't take their medication." (Healthcare worker G)</i>
Medication side effects	<i>"When you take it without food it hurts your tummy. If you take it without food at night, you don't sleep, you feel like there's something slicing up your stomach. Sometimes it comes up to your throat and makes you want to vomit." (Participant S)</i>	<i>"Another thing is medication side effects. Some of them hear people talking about the negative effects of the medication, like people say the meds makes tummies big and gives them humps at the back, so they get scared and stop taking the pills." (Healthcare worker S)</i>
Forgetfulness	<i>"I don't work either but I run a vegetable stall. Sometimes I walk around looking for avocados like now its avocado season. I may get busy, come home late, and forget to take my pills on time." (Participant S)</i>	<i>"Another thing is that some of the clients drink alcohol and you find that they do not adhere to appointment visits because of the drinking, they forget the dates." (Healthcare worker S)</i>
Stress	<i>"Yes I definitely get stressed out when there is nothing to eat. I skip it. One day I took them without food and I felt like I was going to die...feeling the burns. I was burning inside and there was no one to talk to. I thought to myself, this thing is killing me." (Participant M)</i>	
Long distance travel and transportation costs	<i>"I miss the date for clinic visits if there's no money for bus fare. It passes and they yell at me, it's a long way to the clinic, walking there is far especially carrying a child on the back..." (Participant C)</i>	<i>"Some have reported lack of money for transport yet they don't want to use our community ART program because they are afraid of being found out they have HIV. This is common among younger adults and adolescents." (Healthcare worker G)</i>
Gossip in the community	<i>"I agree that here in the community they gossip. They say negative things about you and look at you weird. Even when you are at the hospital taking your kids, they know that if you go into that room you are positive, they then go around gossiping about you in the community." (Participant G)</i>	<i>"They gossip about them. That this one is taking ARVs that why..." (Healthcare worker C)</i>

Maltreatment by healthcare workers	<i>“Another thing I heard people complaining about is poor treatment (being yelled at) by some of the nurses where we pick up the pills. It hasn’t happened to me yet but I’ve seen it happen to someone else. This kind of treatment hurts and its discouraging because nobody wants to be treated like that, even a small child wouldn’t want to be talked to like that.” (Participant S)</i>	<i>“Also poor service at the clinic might be driving some people away. When they come here looking for help and they’re not treated well by the staff, they go back and don’t come back, sometimes for months on end. Sometimes they get yelled at when they arrive at the clinic late. Yet there are things that make them get to the clinic late, things like the issues of disclosure and long distance travel.” (Healthcare worker G)</i>

6.3.2 Quantitative Results

Descriptive statistics

For this study, 166 women receiving ART and residing in rural areas of Swaziland were surveyed (Table 4). A majority of the participants were married/living with a partner (56.6%), with participant mean age of 37 years.

On average, participants traveled approximately 2 hours for clinic visits, with some travelling over 8 hours (range: 0.2-8.1 hours). A majority (66.3%) of the participants reported walking as their main form of travel to and from the clinic, while others mostly used the bus or some other form of public transportation. Of the 166 participants, 23.5% had no formal education, 49.4% attended some primary school, and 27.1% attended some high school. A striking 54.8% of the participants were unemployed, with an additional 18.7% of the participants reporting being limited to seasonal or part-time employment at local clothing factories and sugarcane fields. Of the 166 women, 51.2% occasionally obtained food and/or financial support from family members (including husbands, partners, and relatives), while 10.4% occasionally received help from neighbors, friends, and community members.

Table 4: Demographic characteristics of study participants, n=166

Characteristic	N	Percentage	Mean (SD)
Age	166		37 (7.3)
Travel time	149		1.9 hours (1.7)
Educational level			
No school	39	23.5	
Primary	82	49.4	
Secondary/High	45	27.1	
Marital Status			
Married/ living with partner	94	56.6	
Not married	72	43.4	
Relationship status			
Monogamous	73	45.9	
Polygamous	25	15.7	
Committed	61	38.4	
Employment Status			
Not employed	91	54.8	
Employed full-time	20	12.1	
Employed part-time	20	12.1	
Employed seasonally	11	6.6	
Self-employed	24	14.4	
Household Income			
<=500	91	55.1	
500+	74	44.9	
Alcohol use			
None drinkers	130	78.8	
Drinkers	35	21.2	
ART adherence status			
Adherent	73	44.0	
Nonadherent	93	56.0	
Household food insecurity status			
Food secure	2	1.2	
Mildly food insecure	12	7.2	
Moderately food insecure	46	27.7	
Severely food insecure	106	63.9	
Hunger			
No	45	27.3	
Yes	120	72.7	
Family support			
No	80	48.8	
Yes	84	51.2	

Community support		
No	146	89.6
Yes	17	10.4

Bivariate analysis

Fisher's exact test and Pearson's chi square tests of significance were performed to examine associations between the outcome variable (ART adherence) and independent variables. These tests were also used to determine differences in characteristics between women who were adherent vs. those that were nonadherent (Table 5).

ART nonadherence was significantly higher among women who reported the following barriers to ART adherence: hunger (64.2%, $p=0.000$), hunger-related medication side effects (69.2%, $p=0.000$), clinic too far (81.8%, $p=0.009$), lack of transportation funds (76.9%, $p=0.019$), forgetting to take medication and/or miss clinic appointments (75.7%, $p=0.006$), stress at work/home (78.6%, $p=0.001$), and poor treatment by staff at clinics (79.3%, $p=0.005$). In addition, there were significant associations between: age ($p=0.000$), marriage type ($p=0.016$), location of prescription refill ($p=0.036$), having sex in the previous month ($p=0.001$), and being a subject of local gossip ($p=0.013$). Although not statistically significant, ART nonadherence was higher among women who walked to and from the clinic compared to those who travelled by bus ($p=0.076$).

Table 5: Measures of association between exposure variables and ART adherence

	Adherent		Non-adherent		P-value^a
Exposures	N	%	N	%	
Age	73	44.0	93	56.0	0.000
Hunger					0.000
No	30	66.7	15	33.3	
Yes	43	35.8	77	64.2	
Side effects_no food					0.000
No	37	75.1	12	24.5	

Yes	36	30.8	81	69.2	
Side effects_general					0.514
No	68	44.4	85	55.6	
Yes	3	33.3	6	56.2	
Household food insecurity					0.331
Food secure	1	50.0	1	50.0	
Mildly food insecure	6	50.0	6	50.0	
Moderately food insecure	25	54.4	21	45.7	
Severely food insecure	41	38.7	65	61.3	
Forgetfulness					0.006
No	64	49.6	65	50.4	
Yes	9	24.3	28	75.7	
Stress					0.001
No	64	51.6	60	48.4	
Yes	9	21.4	33	78.6	
Too many pills					0.006
No	72	47.1	81	52.9	
Yes	1	7.7	12	92.3	
Clinic too far					0.009
No	69	47.9	75	52.1	
Yes	4	18.2	18	81.8	
No money					0.019
No	67	47.9	73	52.1	
Yes	6	23.1	20	76.9	
Transport mode					0.076
Walking	43	39.1	67	60.9	
Vehicle	30	53.6	26	46.4	
Travel time	63	42.3	86	59.7	0.188
Transportation costs	73	44.2	92	55.8	0.699
Poor treatment					0.005
No	67	48.9	70	51.1	
Yes	6	20.7	23	79.3	
Experience Stigma					0.078
No	64	45.7	76	54.3	
Yes	6	26.1	17	73.9	
Gossiped about					0.013
No	51	50.0	51	50.0	
Yes	18	30.0	42	70.0	
Community support					0.162
No	60	41.1	86	58.9	

Yes	70	42.9	93	57.0	
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^a p-value from chi-square tests for categorical variables and from two sample t-tests for continuous variables.

Univariate and Multivariate Analysis

Table 6 presents the crude odds ratio (OR) and adjusted OR (AOR) of barriers associated with ART adherence. In crude models, the odds of ART nonadherence was four times higher among women who reported missing doses due to the clinic being too far to travel to pick up monthly medication refills (OR=4.14, 95% CI:1.34-12.84). Similarly, the odds of ART nonadherence was three times higher among those who reported lack of funds for transport as a reason for skipping clinic visits (OR=3.06, 95% CI:1.16-8.08). Although not statistically significant, the odds of ART nonadherence was increased almost five times for women who reported worry/fear of carrying ARVs in public, when compared to those who did not report worry/fear of being seen carrying ARV's (OR: 4.97, 95% CI: 0.58-42.20). Additionally, women who felt stigmatized by friends/community/family members were more than twice as likely to be ART nonadherent compared to those who did not feel stigmatized (OR: 2.39, 95% CI: 0.89-6.41).

In adjusted models, the odds of ART nonadherence were almost three times higher among those who reported skipping taking medication due to hunger/lack of food compared to those who did not skip taking medication due to hunger (AOR: 2.77, 95% CI: 2.32-18.36). In addition, women who experienced hunger-related side effects or sickness from taking ARVs without food, had a 2.9 increase in the odds of ART nonadherence compared to those who did not (AOR: 2.89, 95% CI: 1.09-7.68). The odds of being nonadherent to ART were increased by over five folds for women who experienced poor treatment or being yelled at by clinic staff compared to those who did not report such treatment (AOR: 5.43, 95% CI: 1.41-20.86). Women who reported forgetting taking their medication on time and/or dates of clinic visits were three times as likely to be nonadherent to ART as those who did not forget (AOR=3.01, 95% CI: 1.05-8.62).

Similarly, the odds of ART nonadherence were more than twice as likely among women who: experienced stress at work or at home (AOR: 2.92, 95% CI: 1.07-7.94), and those who felt like they were being gossiped about by relatives, community members and people in their social network (AOR: 2.37, 95% CI: 1.03-5.47) compared to those who did not experience such feelings. Women who travelled by vehicle to and from the clinic were less likely to be nonadherent to ART compared to those who walked (AOR=0.37, 95% CI: 0.15-0.90). Likewise, women who felt supported by community members were 78% less likely to be nonadherent to ART as those who did not feel supported by their communities (OR=0.22, 95% CI: 0.06-0.90). We found significant associations between age and ART nonadherence (AOR=0.94, 95% CI: 0.89-0.99), with younger women being less likely to adhere to ART than older women.

Table 6: Univariate and Multivariate analysis of factors associated with ART adherence among women from rural Eswatini

Factors	Unadjusted Model (Univariate)			Adjusted Model (Multivariate)		
	OR	95% CI	P-value	AOR	95% CI	P-value
Age	0.92	(0.88- 0.96)	0.000	0.94	(0.89-0.99)	0.024
Hunger	3.58	(1.74-7.38)	0.000	2.77	(1.04-7.38)	0.042
Hunger-related side effects	6.94	(3.24-14.84)	0.000	2.89	(1.09-7.68)	0.034
Alcohol use	1.92	(0.87-4.26)	0.097			
No money	3.06	(1.16-8.08)	0.016			
Loud pill container	4.97	(0.58-42.20)	0.085			
Too many pills	4.09	(0.47-35.81)	0.148			
Long lines	4.09	(0.47-35.81)	0.148			
Forgetfulness	3.06	(1.34-7.00)	0.005	3.01	(1.05-8.62)	0.040
Stress	3.91	(1.73-8.85)	0.001	2.92	(1.07-7.94)	0.036
Far	4.14	(1.34-12.84)	0.006			
Poor treatment	3.67	(1.41-9.57)	0.004	5.43	(1.41-20.86)	0.014
Travel time	1.27	(0.89-1.81)	0.184			
Transportation costs	0.99	(0.98-1.01)	0.698			
Transportation mode	0.56	(0.29-1.07)	0.076	0.37	(0.15-0.90)	0.028

Stigma	2.39	(0.89-6.41)	0.071			
Gossip	2.33	(1.19-4.58)	0.012	2.37	(1.03-5.47)	0.043
Avoided	1.35	(0.63-2.93)	0.432			
Family support	1.40	(0.75-2.60)	0.288			
Community support	0.49	(0.18-1.36)	0.165	0.22	(0.06-0.90)	0.034

6.4 Discussion

Our study employed a mixed methods approach to investigate barriers associated with ART adherence among women in rural Eswatini. The sequential exploratory design used in the study enabled us to: 1) explore and understand complex behavioral dynamics influencing decision making, 2) uncover the difficulties that women living with HIV face regarding treatment, and 3) determine the extent to which different factors operating at multiple levels interact and influence ART adherence. Mixed methods allowed for a comprehensive exploration of the phenomenon of adherence to ART among our study participants. Our rich contextual data facilitated identification of key barriers and challenges to compliance with ART faced by rural women living with HIV in Eswatini

Of the barriers identified in our focus groups, nine (hunger, hunger-related medication side effects, feelings of stress, forgetfulness, mode of transport, age, gossip, maltreatment by clinic staff, and community support) were found to be significantly associated with ART adherence. More than half the women in our study were found to be nonadherent to ART (56%), as estimated by the CASE index adherence questionnaire. Previous studies have demonstrated that this measure is able to distinguish medication adherence from nonadherence among individuals in southern Africa(38,46,54). The adherence level we observed in our study was higher than rates that were reported among other studies of ART adherence in southern Africa(36,37,40), but comparable to levels that were reported in a recent study conducted in Eswatini, where 50% of study participants were found to be nonadherent to ART(41).

Our findings indicate that, hunger and shortage of food within the household were reported by both healthcare workers and participants as the primary cause of ART nonadherence. The World Health Organization defines food insecurity as “a situation that exists when people lack secure access to sufficient amounts of safe and nutritious food”, and hunger is defined as “an uncomfortable or painful physical sensation caused by insufficient consumption of dietary energy”(111). While hunger and food insecurity are somewhat different by definition, they are often intertwined and have been shown to exhibit similar negative effects on ART adherence (29,38,92,112,113). With 98.8% of participants classified as living in food insecure households in our study population, and 72.7% of the women having experienced hunger, these data suggest that hunger and household food insecurity are common problems among people living with HIV in rural Eswatini. Furthermore our findings identify hunger as a significant predictor of ART nonadherence.

Nonadherence within our study population seems to occur through three mechanisms: 1) concern over lack of food/ food supply within the household, 2) avoidance of medication/delaying ART when households had insufficient food, and 3) skipping doses altogether when women had no prospects of procuring food (due to financial constraints and inability to obtain food from neighbors). Household food insecurity may affect ART adherence through the impact of inadequate dietary intake. In an effort to prolong household food supply for the whole family, women reported limiting personal meal frequencies and reducing portion sizes, sometimes skipping meals entirely for one or more days to ensure that their children had enough to eat. Other studies in the region report similar findings(12–14), where lack of food and hunger have been found to be significant barriers to ART adherence among individuals receiving treatment(15,93).

Intervention studies providing food supplements and nutritional support have been shown to improve ART adherence(13,14). In a recent World Food Program (WFP) report documenting impact of

the *Food by Prescription* program in Eswatini, food supplementation was shown to significantly improve ART adherence(80). In collaboration with local health facilities, WFP provided food assistance to approximately 2,400 HIV-infected individuals from 2012-2017, an intervention that illustrated that nutritional support was associated with a 16% increase in ART adherence rates among beneficiaries. Overall, these studies show that addressing hunger and improvement in food security facilitates access and adherence to ART thereby improving health outcomes. Our study strongly suggests that immediate increases in food supplement programs would have a dramatic positive effect on ART adherence rates among rural patients in Eswatini.

Facing extreme poverty and hunger on a daily basis while trying to cope with the complex health issues associated with HIV could understandably increase stress levels. Studies indicate that when people are stressed they are more likely to drink, and consequently, forget to take their medication (62,94). Data analysis from our study revealed forgetfulness to be a significant barrier to ART adherence. In our focus group discussions, participants often reported that they were either “too busy or away from home” or “forgot” to take their pills. Healthcare workers echoed participants’ statements, but added that from their observations, alcohol use was the primary reason patients forgot to take their medication. This was supported by some of the women who stated that they sometimes drank alcohol as a way to cope with stress and hunger. Most of the participants in this study had easy access to a cheap alcoholic beverage traditionally made in most rural villages of Eswatini. Although our analysis did not find alcohol use itself to be significantly associated with ART adherence among our study sample, forgetfulness and stress (factors associated with alcohol use) both were. This is consistent with findings from other studies investigating barriers to ART adherence among countries in southern Africa(93,114,115).

Due to the agriculturally based nature of Eswatini, Swazi homesteads are widely spread over much of the arable land. This leads to reduced centralization of health services, resulting in many rural

inhabitants relying on small, understaffed and under-funded clinics located in remote locations of the country. For rural Swazis, it is uncommon to own a car, and most of our study participants reported having to walk or take a kombi (mini-bus) to the clinic for monthly medication pick-up or appointments. For most of the participants, traveling long distances to receive treatment was common, with transportation difficulties reported by both the women and healthcare workers as contributing factors to nonadherence. Indeed, we found significant associations between mode of transportation and ART adherence. Our qualitative analysis revealed that transportation costs were a major barrier to ART adherence, however this association was not significant in quantitative analysis. There are two possible reasons to explain this discrepancy: 1) it is possible that the transportation cost variable may have been underpowered as only 56 observations were analyzed in regression models after taking into account women who did not use public transportation to travel to the clinic, and 2) this relationship could also have been mediated by the availability of Comm ART services which deliver medication to locations closer to patients' homes, thereby reducing the need for women to spend money traveling to the clinic for ART refills. That being said, rates of ART nonadherence were significantly higher among women who walked to the clinic compared to those who traveled by vehicle. In focus group discussions, women reported having to walk to clinics when they lacked sufficient funds to pay for transport. For women living in particularly remote areas, walking to the nearest clinic could take several hours, and was especially difficult on days with thunderstorms or intense heat. Similar findings were reported in a study conducted in Zambia, where patients reported extensive walk times (particularly when traveling in harsh weather conditions) as the main reason they missed clinic visits(12). Several women who faced extensive travel times reported initiating their journey to the clinic before dawn because some clinics/staff required patients to arrive no later than 8am for appointments/medication refills. Clinic staff has occasionally singled late arrivals to wait outside the clinic as punishment, only to be sent away without refills when the clinic closed, wasting an entire day of travel.

Several participants reported being openly reprimanded by clinic staff for missing appointments. We found poor treatment of participants by clinic staff to be significantly associated with ART nonadherence. In group discussions, participants who were either late to or missed appointments often encountered unpleasant experiences with clinic staff, including disparagement, punitive punishment, getting yelled at, and general rude behavior. Some participants stated that legitimate excuses for missed appointments were almost never acknowledged by staff, and then when they did attend the clinic for re-scheduled appointments, clinic staff would utilize the retaliatory punishment of making them wait outside until everyone else had been helped. Maltreatment by clinic staff has been associated with poor health care attendance and has been shown to negatively impact ART adherence(114,116,117). In a recent study conducted among care givers of HIV positive children in Eswatini, patients reported missing/skipping clinic appointments due to fear of getting yelled at and punished by healthcare workers for previously missed clinic visits(103). Additional reports of staff maltreatment included being chastised at monthly pill counts for incorrect number of pills left, consequently, to avoid staff retribution, participants reported discarding excess pills prior to counts. This common practice risks inaccurate data being collected by clinic staff regarding ART adherence rates. Some clinics report high adherence rates, yet staff interviewed at these clinics suspect that actual rates are much lower.

We found significant associations between ART adherence and experiences of gossip and community support in our study. Women who experienced being gossiped about were more likely to be nonadherent to treatment, while those receiving community support were less likely to be nonadherent to ART. Community structures are often important in determining how people behave and what customs they uphold. It is therefore important to understand the traditions and cultures within a community to fully comprehend cultural influences on health behaviors (75,118). In rural Eswatini, communities follow a collectivistic philosophy which promotes connectedness and interdependence, with family (including extended family members) forming the focal point of this social structure(119). In

most rural settings where resources are scarce, families form a valuable support system, which is critical in the management of various life challenges, including ART treatment. Swazis place high value on cultural traditions, cooperation, and conformity, though there is also an emphasis on self-pride; therefore being the subject of any type of gossip (good or bad) is viewed negatively. Relationships with others are emphasized, while personal autonomy, space, and privacy are considered secondary. In rural communities, individuals within families are seen as part of the community, therefore sharing resources and information among families is common. This communal living is conducive to generating gossip, which can be detrimental to infected individuals if relatives, community members, or people in their social network who were entrusted with sensitive health information, share that information with other community members. Our findings are consistent with reports from studies examining ART adherence which also find family/community support to be significant contributors to ART adherence(114,117,120,121).

We also found age to be significantly associated with ART adherence and had a directly proportional relationship to ART adherence i.e. ART adherence increased with an increase in age. Previous studies in sub-Saharan Africa have also reported age as a significant determinant of ART adherence, with better adherence seen among older adults compared to younger people(117).

Strengths

Using a mixed methods approach, we were able to identify and examine key barriers associated with ART adherence among rural Swazi women, providing us with an in-depth and comprehensive understanding of how these barriers interact and influence ART adherence. While a majority of ART adherence studies are conducted in a clinical setting, our study took place within the study participant's own communities, at familiar meeting structures with an aim to provide participants a comfortable environment in which to discuss sensitive and personal information, without fear of judgement and

maltreatment. The sequential exploratory nature of the study design provided a powerful approach to identify potential mechanisms to ART adherence and allowed us to examine the extent to which critical barriers affected ART adherence. Additionally, this study may be one of the first to examine the negative effect that the anxiety surrounding gossip has on ART adherence. Collectively, our findings pinpoint priority areas to target for development, testing, and evaluation of future interventions aimed at increasing HIV medication adherence among one of the most vulnerable segments of Eswatini's population, HIV infected women in rural communities.

Limitations

Temporality is one of the major biases in cross-sectional studies. Because the exposures and outcomes were assessed simultaneously, causality cannot be ascertained from findings of this study. However, the findings of our study are comparable to other cross-sectional studies that have been conducted in sub-Saharan Africa to identify factors associated with ART adherence. This study relies on self-reported adherence rates which may be susceptible to human error and may be influenced by recall bias. While data obtained using the CASE adherence index questionnaire was self-reported, this measurement instrument has been validated and used in previous studies to gather information on HIV medication adherence (142). Studies conducted in southern Africa have demonstrated that this instrument is able to distinguish medication adherence from nonadherence among individuals receiving ART (38,46,54). Though the data triangulation approach (concurrently gathering data from patients and healthcare workers) employed during data collection may have helped strengthen the authenticity of the information obtained as well as the reliability and credibility of the study findings(122).

The ability to generalize these findings may be limited to HIV positive women receiving antiretroviral therapy in rural areas where medication is provided for free in health facilities. The behavioral mechanisms linking hunger, food insecurity, and ART vary with regard to availability and access to antiretroviral therapy. The study could not be generalized to women below 20 years of age, as

well as those in developed countries, or those from countries where HIV medications are not provided for free. The differences in medication access may change the physiology of the population and may have different effects on the outcome.

6.5 Conclusions and Recommendations

The impact of food insecurity and hunger on ART adherence cannot be over emphasized. Providing food supplements and nutritional support have been shown to improve ART adherence. In order to help achieve the government's goal of zero new infections and an end to AIDS by 2022(18), Eswatini must prioritize and invest on strategies aimed at improving food and nutrition security for all HIV-infected individuals.

Insufficient financial resources and lack of food were the main causes of stress for the women in our study. Stress is associated with alcohol use, and was reported by both women and healthcare workers as negatively impacting ART adherence. Our study indicates a need to intensify strategies aimed at identifying and addressing the root causes of stress for people living with HIV. Women living in rural communities at high risk of poor HIV care and management would benefit significantly from programs designed to reduce poverty and unemployment, and increase access to psychotherapy and alcohol rehabilitation programming for infected individuals.

Despite the availability of Comm ART services in most communities, walking long distances to and from the clinic emerged as a significant barrier to ART adherence. While the Comm ART service delivery models have the potential to improve access to ART for those in remote areas, only patients who have proven to regularly take their medication are eligible for this program. Patients defaulting treatment would be deemed ineligible for Comm ART services. We suggest reconsideration of Comm ART enrollment criteria to allow treatment for all ART patients. This could be of substantial benefit for patients defaulting treatment due to financial constraints, particularly those living in remote areas.

Increasing interventions aimed at addressing stigma by raising awareness and acceptance of those living with HIV may reduce patient anxiety toward accessing local ART services in rural communities. In our study, patients frequently reported worrying about being the subject of gossip if seen accessing ART from local clinics or Comm ART locations. Stigma has been shown to inhibit patients' access to ART treatment and leads to nonadherence. In order to encourage the utilization of local ART services and reduce treatment default, it is essential to intensify strategies at both national and local (chiefdom) levels to eradicate all forms of HIV stigma among rural populations.

Women in our study were concerned about a lack of professionalism among clinic staff. Poor treatment by healthcare workers (disparagement, yelling at patients, punitively punishing patients, etc) was reported by many as a contributing factor to nonadherence. Initiatives are needed to retrain healthcare workers regarding professional conduct, sensitivity towards patients' needs, and confidentiality of patients' medical records. Current studies have shown that a good relationship between healthcare workers and patients facilitates adherence(116). Prioritizing a healthy patient-staff relationship would improve service delivery and retention of patients in care.

BRIDGE COMMENT

Our study exposed several barriers to ART, with food insecurity/hunger frequently reported by study participants and healthcare workers as a principal barrier and significant predictor of ART adherence. Food insecurity/hunger has a negative impact on numerous health outcomes including: HIV infection/transmission, ART adherence, and malnutrition, leading to reduction in quality of life and increased morbidity. Retention to care and treatment remains a challenge in Eswatini, with attrition and ART nonadherence rates reported at 30-56%. Studies have shown that widespread food insecurity is key to issues of treatment noncompliance, particularly in sub-Saharan Africa.

Therefore, in the next chapter we discuss issues of food insecurity in Eswatini, in order to raise awareness about the severity of the problem in relation to HIV/AIDS, ART adherence, and nutritional status of people living with HIV/AIDS. We hope information discussed in this chapter will be instrumental in helping the Eswatini government, NGOs, relevant stakeholders, and communities devise sustainable food and nutrition security strategies to improve household food security. Understanding the implications of food insecurity on health may influence policy makers to implement and revise where necessary existing HIV/AIDS and food/nutrition security programs aimed at improving ART adherence and nutritional status among people living with HIV in Eswatini.

While conducting this study and witnessing the hardships faced by the women who participated, it became apparent that having access to sufficient food would be instrumental toward alleviating their plight. By shining some light on these issues, we hope to move a step further (both in knowledge and approach) toward winning the battle against HIV/AIDS through strengthening and developing policies that will incorporate food and nutrition security interventions in HIV/AIDS programs.

CHAPTER 7

MANUSCRIPT 3

FOOD AND NUTRITION SECURITY IN ESWATINI IN THE ERA OF HIV/AIDS AND ART

7.1 Introduction

Human Immunodeficiency Virus (HIV) is a significant health burden faced by millions of people globally(1). Despite substantial progress in the fight against HIV, Eswatini remains the country with the worst prevalence and incidence rates in the world. Currently, adult HIV prevalence among countries in southern Africa is estimated to range from 9.2% to 27.2 %, with Eswatini bearing the highest burden at 27.2%(3). For the past two decades, the Eswatini government has invested heavily in programs aimed at combating HIV/AIDS, including free access to HIV medication and clinical treatment to all HIV positive individuals. At present, an estimated 87.4% of citizens living with HIV are receiving ART in health facilities across the country(3).

Over the years, the Ministry of Health, in collaboration with the private sector and non-governmental organizations (NGOs), has employed strategies aimed at increasing ART coverage and decentralizing HIV care services to regional health facilities, with special focus on underserved rural communities. Country wide campaigns targeting increased awareness of HIV testing and counseling, prevention of mother-to-child transmission, and voluntary male circumcision have been implemented, along with interventions aimed at widespread increase in access to ART services. Collectively, these national level initiatives and programs have led to significant progress in the prevention of new infections, and in ensuring treatment access to all HIV-infected individuals(3). Unfortunately, little progress regarding the trajectory of HIV prevalence has been observed thus far. According to the Swaziland HIV Incidence Measurement Survey (SHIMS) report, HIV prevalence rose from 49% among

females 35-39 years of age in 2011/2012 to 54.2% among females of the same age group in 2016/2017(3,123). Given that numerous HIV/AIDS programs have been established in the country's efforts to make significant strides in controlling HIV/AIDS, it would be expected that much lower HIV rates would be realized than currently exists. The question becomes, how is it that after decades of concentrated efforts combatting the HIV/AIDS pandemic, Eswatini remains the nation with the highest incidence and prevalence rates in the world?

Previous studies have identified several factors influencing HIV/AIDS and ART treatment in Eswatini(41,44,124). Frequently reported as a significant factor, food insecurity (inadequate access to food of sufficient quantity/quality or inability to acquire food in a socially acceptable way), has been identified as both a risk factor for HIV transmission and a significant barrier to ART adherence(29,41,49,124). Food insecurity is widespread in Eswatini. Approximately 71% of Eswatini households were identified as food insecure in 2016/2017, with an average consumption of 2.5 and 3.5 meals per day for adults and children, respectively (9).The number of meals consumed were below that of recommended proportions for improved nutritional status and health outcomes among individuals across all ages. Greater eating frequency of 5-6 times per day (3 moderate nutrient-dense meals, and 2-3 nutritious snacks between) is associated with lower risk of overweight/obesity as well as nutrition-related ailments (NR-NCDs)(125–127). Combatting pervasive food insecurity is no small task in a country with an unemployment rate of 28% and where 69% of the population lives in extreme poverty (less than \$3 per day)(21).

There is a lack of commitment by the Eswatini government to prioritize Food and Nutrition Security. The Eswatini National Nutritional Council was established by the government to promote and coordinate food and nutrition programs in the country. Unfortunately due to budget cuts, operation of the organization is now dependent upon donor funds, which are often unreliable. The purpose of this paper is to provide context of how food insecurity is a driver of HIV/AIDS, ART adherence, and poor

nutritional status among people living with HIV/AIDS. Firstly, we present multilevel factors influencing food insecurity and their interrelationship with HIV/AIDS, nutrition/nutritional status, and ART. We then examine to what extent current national policies are evidence driven and supportive of critical health behaviors, such as sustained uptake of HIV treatment and adherence to ART by citizens living with HIV, particularly in vulnerable sub-populations such as HIV-infected women in rural communities. Finally, we provide recommendations for inter-sectoral and multilevel policies that are supportive of improved adherence to ART which may in turn impact the trajectory of the nation's HIV rates over the long term.

7.2 Food Insecurity, Vulnerability of Women, and HIV/AIDS

The effects of food insecurity on HIV/AIDS and vice versa have been well documented. Food insecurity heightens susceptibility to HIV exposure and infections, and HIV/AIDS in turn amplifies vulnerability to food insecurity(49,50). When people in their productive years are too sick to work or die prematurely from AIDS, it leads to decreased household income, increased healthcare expenditures and/or loss of head of household income. These changes in household finances have a profound impact on food availability, and thus increasing the risk of food insecurity among families impacted by HIV/AIDS (110). Household food insecurity is associated with inadequate food/dietary intake and can negatively impact a person's ability to cope with HIV, as effective treatments depend on adequate food intake(128–130).

The alarming reduction in productivity resulting from high HIV/AIDS related morbidity and mortality rates in Eswatini leads to deeper and persistent levels of poverty, leaving caretakers and surviving family members more vulnerable to the adverse effects of HIV, thus threatening individual and household food security. Furthermore, food insecurity has been linked to high-risk sexual behavior among women(124), with evidence indicating that women living in poverty often resort to transactional sex to financially support themselves and their families. Moreover, many young women engage in inter-generational sexual relationships with older men who give them food, money, or gifts. The financial

dependency created in such relationships mean the young women have little to no power to negotiate condom use, hence increasing their risk for HIV infection and or transmission(25).

Within households, food insecurity has been shown to be a significant contributor to intimate partner violence (IPV). Women in food insecure households are more likely to experience emotional and physical abuse at the hands of their intimate partners. Lack of food in the household, poor food preparation/presentation/portion size allocation, and withholding of food/money to buy food has been documented as major triggers of violence (beating of wives by spouse/partners) among heterosexual couples (79,131). Among adults 15-49 years, 1 in 4 women experience physical violence from their husbands or partners in Eswatini(27). In addition, alcohol use is highly prevalent in Eswatini, with men comprising the majority of drinkers(132), and women whose husbands drink alcohol more likely to report IPV.

Swazi values and norms uphold men's privileges and have tended to constrain women's autonomy. Culturally, men are regarded as decision-makers and heads of the households. They are expected to go to work, and generally regulate resource use (such as distribution of farming plots within the family land), and make major decisions regarding both food production (types of crops grown) and economic expenditures. Women often stay at home and manage household chores such as cleaning, cooking, collecting water and firewood, ploughing the fields, and looking after the children(25). In addition, with permission from their husbands, poor women often work local seasonal jobs in order to supplement the family income. Since there are little enforcement of child and family protection laws in Eswatini, decisions for provision of financial support are often left entirely to the men. These practices lead to women being financially dependent on men and at increased risk of physical and emotional abuse(25,27).

When husbands die from AIDS, often the man's family members blame the wife for being promiscuous and infecting their husbands with HIV, regardless of whether the accusation is based on

fact or not. For women living with HIV this is particularly challenging, as they are often stigmatized as immoral and ostracized from their families simply due to being diagnosed with HIV/AIDS(23,29). Not only does this impact family dynamics with regard to adult relationships, but also affects the lives of their children as well. Women from food insecure households in highly constrained environments (uneducated women in rural communities) are often forced to make risky choices that help them navigate violence, thereby putting themselves at risk for HIV infections.

In most families with HIV-infected parents, children have to endure the physical and psychological distress of having to care for their ailing parents. Approximately 19% of children in Eswatini are orphaned and vulnerable children (OVCs), with an estimated 40, 233 children being AIDS orphans(90). When a parent dies of an AIDS related illness, often a child becomes head of the household and therefore forced to take on the responsibilities of a parent leaving their childhood behind. The older siblings have to look after their younger siblings, and must secure an income in order to feed, clothe, and educate them. They are forced to take on the responsibilities of a parent and must leave their childhood behind. Therefore, food security interventions could be used as a response strategy to prevent and manage HIV/AIDS, end violence against women, as well as strengthening family relationships.

7.3 Food Insecurity, Nutrition, and HIV/AIDS

The direct impact of household food insecurity on dietary intake among individuals has long been recognized. Studies conducted in Eswatini have found household food insecurity to be associated with experiences of hunger, high risk sexual behaviors, and malnutrition(29,110,124). Food insecurity does not only impact an ability to consume adequate nutrients, it also increases a person's risk to poor nutritional status and susceptibility to infections including HIV/AIDS(133,134). The interaction between HIV/AIDS and nutrition can be viewed from two perspectives: 1) biological dynamics which include associations between nutritional status, risk of infection, and evolution of the disease such as increased

resting energy expenditure, reductions in food intake, nutrient malabsorption and loss, and complex metabolic alterations that lead to weight loss and wasting; and 2) a socioeconomic perspective, which considers consequences of the disease related to food and nutrition security of affected households and communities through lack of food, increased spending on HIV/AIDS, and reduced family incomes and savings (due to increased morbidity and mortality)(50,133,135). Inadequate nutrient intake is recognized as a major contributor to the development of malnutrition among HIV-infected individuals. Undernutrition (including nutrient deficiencies, marasmus and wasting), the most common form of malnutrition in Eswatini, is associated with weakened immune system, increased morbidity, and adverse effects of HIV. Untreated HIV infection increases nutrient requirements while decreasing appetite and, in more advanced stages, limiting food intake and absorption of nutrients(134,135).

Among other factors, HIV/AIDS and malnutrition are significant contributors to the high mortality rates observed in Eswatini, 67 deaths per 1000 live births for children under age 5 and 486 per 1000 adults(136). Over the years, the healthcare sector in Eswatini has been burdened with increased prevalence of illnesses associated with AIDS. The admission of AIDS patients to healthcare facilities remains high throughout the country, with approximately 3900 people dying from AIDS related illnesses in 2016. The impact of the epidemic has been so severe that life expectancy dropped from 60 in the 1990s to 49 in 2015(90).

Research evidence has shown that HIV infection, onset of AIDS, and even death can be delayed among well-nourished HIV positive individuals(137). Deficiencies of vitamins (A, B-complex, C, and E)and minerals (selenium and zinc), required by the immune system to fight infections, are common in people living with HIV(134,138). Deficiencies of antioxidant vitamins and minerals contribute to oxidative stress, a condition that accelerates immune cell death and may increase the rate of HIV replication among infected individuals(139). Therefore, adequate dietary intakes of macro and

micronutrients are essential to strengthen the immune system and help the body fight against opportunistic infections among people living with HIV/AIDS(140).

Nutritional support and supplementation may help prevent the development of nutritional deficiencies, AIDS-related weight loss/wasting, and can help improve quality of life for people living with HIV(49,87,133). In most countries in southern Africa, including Eswatini, HIV medications and nutritional counseling are widely available at no cost to all infected individuals. However, access to food and nutrition support/vitamin supplementation is very limited and sometimes only available for undernourished HIV/AIDS and TB patients. While nutritional counseling plays an important role in assisting people living with HIV/AIDS improve and maintain good nutritional status, better access to medical care and food and nutrition security are crucial for successful treatment and management of HIV/AIDS.

7.4 Food Insecurity and ART

Food insecurity can affect ART adherence directly, through its impact on food/nutritional intake, and indirectly, by exacerbating side effects from HIV medication(14,49). Food insecurity leads to inadequate dietary intake and nutrient deficiencies. While food and nutrients play a significant role in the metabolism of drugs and their distribution in the body, deficiencies such as inadequate protein intake results in low serum albumin levels (plays an important role in drug transport and metabolism), and may lead to an increased risk of side effects from antiretroviral treatments(128,141). A growing body of evidence indicates that food insecurity increases the risk of HIV transmission, ART nonadherence, and leads to negative health outcomes such as increased HIV replication, heightened disease progression, reduced viral load suppression, and increased morbidity among people living with HIV/AIDS(105,142,143).

Among studies conducted in Eswatini, food insecurity has been associated with ART nonadherence, intergenerational sex, sex exchange for food and money along with inconsistent condom

use, all of which increases the risk of HIV infection among women(143). Nonadherence to HIV medications results in treatment interruptions and missed clinic visits, which lead to increased susceptibility to infections and overall poor health outcomes. While the Swazi government provides free ART treatment for all living with HIV, most individuals are required to travel to the clinic for medication refills. Those living in remote areas often travel using public transportation and must pay for transportation out-of-pocket as these costs are not covered by the free government programs. Scarce financial resources and insufficient food access coupled with increased demand for care can make it extremely difficult for individuals to prioritize chronic health costs. Food insufficiency may result in a shift away from financing long-term health care to spending money on necessities to ensure a stable household food supply(133).

For example, families with limited financial resources may choose to spend money on food and food-related activities (such as farming) instead of expending scarce financial resource on HIV treatment and care. In our study conducted in Eswatini, rural women reported having to choose between using their limited income on paying for transportation to the clinic versus being able to adequately feed themselves and their children. As a result of these difficult choices, some women in the study missed health care appointments and were unable to pick up their antiretroviral medications. As a coping strategy, women from food insecure households reported reducing meal frequency and portion sizes for themselves in an effort to prolong the household's food supply. Similar findings were reported in a study conducted in South Africa, where researchers found that decreasing food variety, reducing portion sizes, and skipping of meals were coping strategies that women used to overcome food insufficiency in the household. Food deprivation and anxiety over food supply can lead to stress, which may contribute to ART nonadherence, increased disease progression, and adverse health outcomes among infected individuals(54).

7.5 Food Insecurity, Nutrition Transition, and ART

In addition to the high prevalence of HIV (with a significant proportion of the population receiving ART in Eswatini), the country has also been struggling with extremely high rates of food insecurity and a double burden of malnutrition (both undernutrition and overnutrition). The problem of malnutrition and HIV in Eswatini is at an alarming level due to current crises arisen from repeated drought leading to food shortages and wide spread poverty(10). However, it is worth mentioning that, even in years of reasonable harvest (years prior to the drought), a majority of Swazi households still lived below the poverty line and high levels of food insecurity. Food insecurity leads to malnutrition (both under-and over-nutrition). While undernutrition leads to nutrient deficiencies, overnutrition has been associated with an increased risk of overweight and obesity among individuals(144,145). Currently in Eswatini, the prevalence rates of both forms of malnutrition are at an alarming rate, as approximately 26% of children under age 5 are stunted (low length/height- or-age), 2% are wasted (low weight-for-length/height) and 6 % are underweight (low weight -for-age), with an estimated 44% and 21% of the Swazi adult population being overweight or obese(79,146).

Defined as a situation that occurs when undernutrition and overnutrition coexist, the nutrition transition has been linked to increased rates of overweight and obesity among individuals, including those living with HIV(147–149). Food insecurity has been associated with increased energy intake/consumption of energy-dense foods, which are the main cause of overweight and obesity and risk factors for numerous nutrition-related non-communicable diseases (NR-NCDs) including metabolic syndrome, cardiovascular diseases (CVD), osteoporosis, some cancers, and other chronic diseases such as type 2 diabetes mellitus (T2DM) and hypertension(147,149). Components of the nutrition transition that are negatively associated with NR-NCDs, particularly as a result of overweight and obesity have been well documented(149). Adverse dietary changes, including shifts in dietary patterns toward increased consumption of energy-dense foods (e.g. foods high in saturated fats, added sugars and

sodium) and reduced consumption of nutrient-dense foods (e.g. fruits, vegetables, and dietary fiber), in addition to lack of exercise/minimal physical activity have been associated with increased risk of NR-NCDs.

In Eswatini, there has been a drastic increase in overweight and obesity rates over the past years, with women more overweight (59.9% vs 26%) and obese (30.9% vs 8.8%) than men(146). Overweight and obesity have been linked to numerous health risk factors for CVD, stroke, T2DM, hypertension, pulmonary diseases, osteoporosis, and certain cancers(149). This is a major public health issue as Eswatini has the highest rates of both HIV and overweight/obesity, the two major health conditions associated with numerous communicable and non-communicable diseases in the region and worldwide(3,146,150). Studies have shown that people on ART treatment are as susceptible to overweight and obesity as non-infected individuals, and are significantly affected by adverse effects of these health conditions(151). HIV-infected individuals are often in a compromised state of health making them susceptible to malnutrition due to a combination of inadequate nutrient intake, HIV medication side effects, and compromised immune systems(148,152). Therefore, the occurrence of NR-NCDs as a result of the nutrition transition can create additional stress to the already weakened immune systems of HIV-infected individuals, thereby increasing the risk of morbidity and mortality among this population.

7.6 Progress in Policy work

There has been some progress in the formulation and implementation of relevant policies to address Health, HIV/AIDS, and Food and Nutrition Security in Eswatini (Table 7). Over the years three policies (Health, HIV Prevention, Food and Nutrition Security (draft) have been formulated and revised to meet the health demands of the population.

Table 7: Current programs for Health, HIV/AIDS, and Food and Nutrition Security in Eswatini

Programs	Target population	Aim/Objective
HIV/AIDS		
Adoption of the National HIV Prevention Policy	Everyone.	Guiding the design, implementation, and management of HIV prevention programs.
HIV testing and counseling	Everyone.	Increasing awareness and HIV prevention.
Test and start		Increasing HIV testing and ART initiation.
Mothers-to-mothers (M2M) programs in health facilities	All pregnant and lactating women.	Prevention of mother-to-child transmission of HIV.
Voluntary male circumcision	All males.	HIV prevention.
Community-centered ART service delivery models (Comm ART)	Stable patients receiving ART.	Tracking treatment defaulters and improving ART retention rates.
Food and Nutrition Security		
Food assistance (food donations, food-for-work, cash vouchers, and food-for-training activities)	OVCs and poor households, particularly in rural areas	Improving food and nutrition security for vulnerable populations.
Agricultural farm inputs for community-based projects (communal gardens & livestock production, OVC fields)	OVCs and poor households, particularly in rural areas.	Improving food and nutrition security for vulnerable populations.
Food-by-prescription	Malnourished children and malnourished HIV/AIDS and TB patients.	Treatment and disease management. Improving nutritional status of vulnerable patients.
School feeding	Primary and high school students.	Improving food and nutrition security for school-going children.
Vitamin supplementation	Children, Malnourished individuals, and pregnant and lactating mothers.	Treatment and disease management. Improving nutritional status of vulnerable patients.
Food fortification for staple food (corn-based products) and most foods.	For everybody	Improving nutritional status of the population.

* Stable patients-individuals that have been on ART for at least a year, have not missed clinic appointments, and have undetectable viral loads.

*OVCs- Orphaned and Vulnerable Children

7.6.1 National Health Policy

The National Health Policy was initially published in 1983 and revised in 2005. The objectives of this policy were to: provide health education, promote food supply and proper nutrition, improve access to clean water and basic sanitation, promote maternal and child health, and improve treatment of common diseases including treatment for both communicable (tuberculosis, HIV and other sexually transmitted diseases) and non-communicable diseases (T2DM, hypertension, CVD, and respiratory diseases). The policy also aimed at improving equitable distribution of health services and coordinating the public and private sectors, in order to ensure improved health service delivery and interventions as well as resource mobilization. Since then, this policy has been used as a guide for the establishment of and implementation of numerous programs aimed at reducing and eliminating HIV/AIDS in Eswatini(153).

7.6.2 National HIV Prevention Policy

This first National HIV Prevention Policy for Swaziland was published in 2012, with an aim to strengthen strategies employed in the country's fight against HIV and AIDS. The policy provides broad guidelines for the design, implementation, and management of HIV prevention interventions and programs across multiple levels. This policy was informed by currently existing HIV response documents which included the: Swaziland National Multi-sectoral Strategic Framework for HIV and AIDS, Swaziland HIV Estimates and Projections Report, Swaziland HIV Prevention Response and Modes of Transmission Analysis, and Swaziland Demographic and Health Survey(154).

Since 2003, a National Strategic Framework guided interventions designed to prevent the spread of HIV and reduce the adverse socioeconomic effects of the epidemic. This framework is evaluated and re-designed every five years. The current 2014–2018 extended National Strategic Framework employs a human development approach to implement biomedical, behavioral, social, and structural interventions aimed at eliminating new HIV infections and eradicating AIDS(90).

In an effort to eradicate HIV, Eswatini has adopted the UNAIDS 90/90/90 targets to ensure that 90% of HIV positive individuals know their status, 90% of those eligible receive ART, and 90% of those on treatment achieve viral suppression. These new targets are aimed at helping to reach the government's goal of zero new infections and an end to AIDS by 2022. Additionally, to further facilitate the process, the country has adopted the concept of reaching zero new infections, zero stigma and discrimination, and zero deaths, which is commonly known as 0:0:0(90). Over the past decade, the Ministry of Health (collaborating with NGOs and the private sector) has implemented strategies to increase ART coverage and decentralization of HIV care services to lower level health facilities, particularly those in rural areas. In 2015, the country implemented the Test and Start program aimed at increasing HIV testing and ART initiation immediately after a positive diagnosis. This program has greatly facilitated the scaling up of ART programs and has helped reach thousands of people living with HIV/AIDS.

While intervention strategies have been adopted by the Swazi government and private organizations to help combat the spread of the pandemic and its associated consequences, lack of compliance to treatment continues to be a significant challenge for HIV programs throughout the country. Currently, the percentage of patients remaining on treatment after ART initiation decrease over time (i.e. as duration on ART increases, ART retention rates decreases)(6). In tackling the problem of defaulters, the government has recently implemented community-centered ART service delivery models. Known as Comm ART, this service is aimed at increasing access to ART and improving retention rates for all HIV positive patients, particularly those in remote areas. However, only patients that are evaluated as stable after 12 months of clinic visits are eligible for Comm ART services, where they may receive 3 month supply of medication per visit, while unstable patients are required to continue monthly assessments at the clinic(81).

Under this program, patients are classified as stable if they have been on ART for at least a year, have not missed clinic appointments, and have undetectable viral loads from the most recent

consecutive tests (with the most recent test taken within the past six months). It is worth noting that, while these programs have the potential to improve ART adherence, their successful implementation is dependent on numerous factors that have been shown in the literature to impact and influence health behavior. Our study conducted in Eswatini with a highly vulnerable population of rural women has shown that access to and utilization of treatment may be influenced by risk factors operating at multiple levels (the individual, household, and community/structural levels). At the individual level, these include: hunger/lack of food, denial, fear of HIV medication side effects, stress, alcohol use, forgetfulness, and stigma (perceived/experienced). Similar findings are documented for other age groups and segments of the population in the country(29,41,44). At the household level, barriers to treatment compliance include: household food insecurity, socioeconomic status, lack of disclosure/accidental disclosure of HIV status, living in polygamous/large families, lack of financial resources, and poverty(29,41,44). At the community level, these include: lack of privacy and confidentiality, maltreatment by healthcare workers, long distance travel and transportation costs, poor community support services, and gossip (at the individual-, household-, and community level)(29,41,44).

7.6.3 National Food and Nutrition Policy

In an effort to respond to the nutritional needs of the Swazi population, the government established the Eswatini National Nutrition Council (ENNC) through the Act of Parliament of 1945 which is mandated to promote and coordinate food and nutrition activities as well as providing technical advice to the government regarding Food and Nutrition Security issues in the country. The specific mandate of the ENNC is to ensure that strategies and policies are developed and operationalized to improve the nutritional status of the people of Eswatini. After consultation with relevant stakeholders (including government ministries, civil societies, NGOs, and the general public), the organization has put forward a National Food and Nutrition Policy, which since 2009 remained in draft form and not yet adopted by the Eswatini government(155). Despite the slow progress towards finalizing the policy,

numerous food and nutrition interventions have been implemented over the past decades, some by a few agencies under the Ministry of Agriculture, but mainly by foreign organizations from various UN agencies (WFP, FAO, and UNICEF) as well as American and European based NGOs. These interventions are aimed at improving food and nutrition security for vulnerable populations in the form of food assistance programs (food donations, food-for-work/training activities), provision of agricultural farm inputs for community-based projects, food assistance for HIV/AIDS and TB patients (food-by-prescription), and school feeding programs. However, due to the recent financial world crisis and issues regarding excessive spending on luxurious projects by the Swazi government, there have been significant reductions in aid and donations from foreign NGOs. In addition, since Eswatini has been recently classified as a middle income country, the expectation from the international community is that the country should now take over and allocate sufficient resources to sustain programs previously funded by foreign organizations. Unfortunately, very little progress has been observed so far, given that approximately three quarters of Eswatini households remain food insecure, and with two thirds of the population still living in abject poverty(156).

7.7 Challenges and Gaps

Through rapid response in implementing targeted interventions including HIV testing and counseling, prevention of mother-to-child transmission, voluntary male circumcision, and increasing ART provision and services across the country, Eswatini has made significant progress in preventing new infections and ensuring treatment access to all infected individuals. ART has been free in Eswatini since 2003, and has been provided to all HIV-infected individuals regardless of CD4 count since 2015. With all the interventions implemented over the past few decades, significant progress should become apparent with improvement in a range of health outcomes across the board. However, this is not the case, as

Eswatini remains the only country with the highest HIV incidence, prevalence, and AIDS-related morbidity and mortality rates both in sub-Saharan Africa and in the world.

As far as nutrition is concerned, overlaps in policy formulation can be seen among the three policies discussed above. The goal of the National Food and Nutrition Policy has a common objective that implies a rapid and substantial reduction in the degree and severity of malnutrition, in all its forms. The National Health Policy for instance, is designed to promote food supply and proper nutrition for improving health and nutritional status. The scope of the National HIV Prevention Policy is to upscale HIV treatment care and support, and to provide nutritional support for people living with HIV/AIDS. These overlaps in policy are often too wide and challenging for effective implementation of nutritional programs. In order to maximize the contribution of food and nutrition programming to HIV/AIDS impact mitigation, Eswatini needs to consider a more sector-specific approach to policy and programmatic responses to HIV and nutrition. The incorporation of nutrition programs under the Ministries of Health and Agriculture for instance, poses challenges in effective implementation of these programs. One problem of incorporating nutrition programs in food security is that, food security programming is not as strong in many countries, including Eswatini. Programming for food and nutrition security rather than just agricultural production is difficult due to the multi-sectoral nature of the issues(157).

That being said, in the food and nutrition sector the much bigger challenge is the lack of adopted Food and Nutrition Security policy and the political will to advocate for investment in food and nutrition security programs as well as the lack of resource allocation by the Eswatini government. Furthermore, the lack of collaborative relationships among relevant organizations working in food and nutrition interventions (particularly NGOs who often work in silos) makes it difficult to coordinate, monitor, and gather up resources for effective implementation of these programs.

In addition, access to basic human needs (such as food and safe water) continues to be a major problem in Eswatini, particularly among rural households who are the most vulnerable. There is ample evidence to suggest that the distribution of health resources tends to favor urban over rural based populations(6,79). The national health system is often unresponsive to the needs of most of the population (due to insufficient staffing and recurrent drug shortages in healthcare facilities) and contributes to vulnerability and impoverishment(158,159). Residents of rural areas often have increased travel distance and time compared to urban residents. Urban settings tend to have in place infrastructure that facilitates increased access to public transportation, resulting in greater access to health facilities, which collectively may increase health seeking behavior among HIV infected individuals. Greater distance to one's health care facility has been associated with poor health care access and negative health outcomes among HIV positive individuals in Eswatini(41,44).

According to the World Health Organization, Eswatini healthcare system ranks among the 50 worst health systems, and has been reported as being the least healthiest country in the world(160,161). The country's health facilities are often challenged with significant human resource constraints and medication shortages, including ARVs. Recently, there has been increasing reports of shortages of ARVs in health facilities across the country as well as massive protests by nurses and the public calling upon the Ministry of Health to address the shortages of drugs and nurses in government hospitals(158,162,163). For HIV/AIDS patients, it is imperative that their medicine supply is not interrupted as shortages of ARVs could have serious implications that may negatively impact: 1) ART adherence (individuals getting anxious and feeling discouraged to pick-up and take ARVs), 2) HIV transmission (may lead to unsuppressed viral loads and increased risk of infections), and 3) HIV treatment (virus developing a resistance due to treatment interruptions). This is a national crisis that the Eswatini government must resolve immediately, and put in place strategies to ensure that drug shortages never happen in the future.

7.8 Recommendations

7.8.1 Improving Food and Nutrition Security

The need to improve food and nutrition security of the Swazi population is urgent, in particular for poor and vulnerable groups. Research supports the provision of food and nutrition assistance as a promising intervention to prevent and treat HIV among individuals(95,129,135). Therefore there is a critical need for the Eswatini government to act promptly and adopt the Food and Nutrition Security policy, a necessary framework to help guide, strengthen, and coordinate food and nutrition programs across the country. However, in light of the current situation regarding the effect of the nutrition transition in Eswatini, this policy must be revised to incorporate food and nutrition strategies that also address NR-NCDs. The cost burden of not efficiently addressing food and nutrition insecurity is enormous(9) whereas early and focused food and nutrition interventions have been shown to improve health behavior and may lead to increased productivity and reduced healthcare costs, which could make an important contribution to economic progress(164–166). While adequate food and nutrition cannot cure HIV infection, it is essential for maintaining a healthy immune system, and achieving optimal quality of life. Food and nutrition security holds great promise as a mechanism to reduce high-risk sexual behaviors, improve treatment and ART adherence, and help control the HIV epidemic in Eswatini.

7.8.2 Addressing Barriers to ART Adherence

The benefits of early ART initiation are not only improved individual patient outcomes but also reduced infectiousness and therefore decreased HIV transmission. Social and structural barriers as well as individual-level behaviors affect access to and use of HIV treatment (Figure 10). Overcoming such barriers can yield substantial health gains for people living with HIV, therefore targeted interventions are needed to address existing barriers to healthcare access and utilization in Eswatini. For instance, increasing interventions aimed at addressing stigma by raising awareness and acceptance of those living with HIV may reduce patient anxiety toward accessing local ART services. In our study, worry concern

over being the subject of gossip if seen accessing ART from local clinics or Comm ART locations was frequently reported by women as a significant barrier to ART adherence. Stigma has been shown to inhibit patients' access to healthcare services including HIV testing and ART treatment. In order to encourage the utilization of local ART services and reduce treatment default, it is essential to devise strategies at both national and local (chiefdom) levels to eradicate all forms of HIV stigma among rural populations.

Currently, a majority (two thirds) of the population in Eswatini live below the poverty line. Unemployment and inadequate incomes increases the risk of people contracting and spreading HIV, and also encourages the adoption of survival strategies that expose people to other health risks. Insufficient financial resources and lack of food were the main causes of stress for the women in our study. Stress is associated with alcohol use, and was reported by both women and healthcare workers as negatively impacting ART adherence. In addition, alcohol use has been associated with increased domestic violence as well as food insecurity (men spending money on alcohol and casual sex partners instead of food for the family). Our study indicates a need to intensify strategies aimed at identifying and addressing the root causes of stress for people living with HIV. Individuals living in rural communities at high risk of poor HIV care and management would benefit significantly from programs designed to reduce poverty and unemployment, and increase access to psychotherapy and alcohol rehabilitation centers for those living with HIV.

7.8.3 Improving Access to Healthcare and Healthcare Delivery

Access to healthcare impacts one's overall physical, social, and mental health status and quality of life. Improved quality and effectiveness of healthcare systems is important for promoting and maintaining health, preventing and managing disease, and reducing morbidity and premature death(164). Improving access to healthcare services depends in part on ensuring that people: 1) are diagnosed and treated promptly, 2) have a usual and ongoing source of care, and 3) can obtain quality

preventive care early enough to avoid illness or complications. In addition, an effective healthcare system should also ensure that services are offered within a reasonable distance from where people live(164).

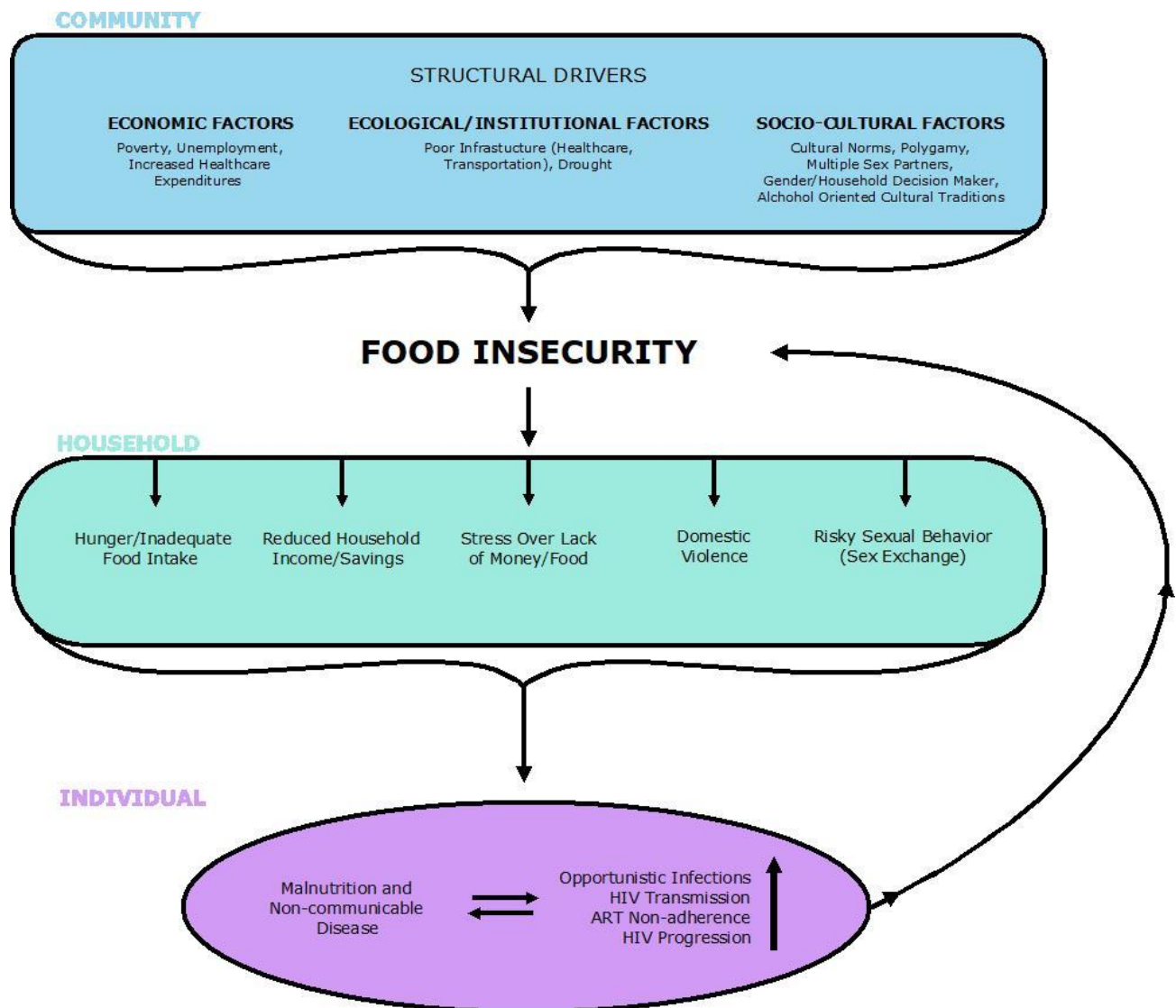
It is therefore important that existing programs are strengthened to ensure that people living with HIV receive quality healthcare throughout their life-span by providing technical assistance and other supports to healthcare workers to foster accessible, comprehensive, integrated, and patient- and family-centered medical care. While the Comm ART service delivery models have the potential to improve access to ART for those in remote areas, only patients who have proven to regularly take their medication are eligible for this program. Patients defaulting treatment would be deemed ineligible for Comm ART services. Perhaps Comm ART enrollment criteria could be altered to allow treatment for all ART patients. This could be of substantial benefit for patients defaulting treatment due to financial constraints, particularly those living in remote areas.

In our study, lack of confidentiality was reported as a major reason patients missed clinic appointments and discontinued accessing ART from local clinics. Women in our study were concerned about a lack of professionalism among clinic staff. Poor treatment by healthcare workers (disparagement, yelling at patients, punitively punishing patients, etc) was reported by many as a contributing factor to nonadherence. Initiatives are needed to retrain healthcare workers regarding professional conduct, sensitivity towards patients' needs, and confidentiality of patients' medical records. Current studies have shown that a good relationship between healthcare workers and patients facilitates adherence(116). Prioritizing a healthy patient-staff relationship would improve service delivery and retention of patients in care. Healthcare workers should be retrained to be more compassionate and understanding of the challenges HIV patients face.

7.8.4 Improved Collaborative Relationships

Eswatini should also look into strategies to improve health infrastructure and strengthen collaborative relationships between the Ministries of Agriculture and Health, the Eswatini National Nutrition Council, and NGOs working in food and nutrition programs for effective implementation, monitoring, resource sharing and evaluation of projects. All health and nutrition projects should include the involvement of beneficiaries and partners in the planning, funding, monitoring, and evaluation of all health and nutrition programs. Focus should be on community participation from the planning stage and throughout the process when setting up food and nutrition programs. This engagement is the key to ensuring that programs are well received, and that community members will continue to be invested in the long-term success of these programs.

Figure 7: Conceptual Framework for Impact of Food Insecurity, Malnutrition, and HIV/AIDS Interactions across Multiple Levels



* Framework adapted from conceptual framework for food insecurity and HIV/AIDS linkages illustrated by Weiser et al (2011).

7.9 Proposed interventions

Individual level:

- Revitalize programs to focus on providing supplemental food and nutrition support for low-income families in the country.

- Integrate food supplementation in HIV/AIDS programs (expand food-by-prescription program, provide food rations for low-income families impacted by HIV).
- Increased education and awareness focusing on educating the public regarding HIV/ART, nutrition, and non-communicable diseases.

Household level:

Intensify strategies aimed at identifying and addressing the root causes of stress and food insecurity for people living with HIV, such as:

- strengthening existing programs to reduce poverty and unemployment
- implementing policies to end gender based violence
- strengthening and enforcing child and family support laws
- strengthen existing community-based nutrition programs by increasing local food production

Community/Institutional level:

- There is an urgent need for the Eswatini government to adopt the Food and Nutrition Security policy and allocate resources in the yearly budget for food and nutrition security programs
- Intensify strategies at both national and local (chiefdom) levels to eradicate all forms of HIV stigma/negative gossip in the nation, particularly among rural populations (raising awareness and acceptance of those living with HIV)
- Comm ART should be expanded to additional communities and opened up to patients of all levels of adherence

- The burden of transportation costs need to be alleviated for HIV/AIDS patients (providing cash vouchers to cover transportation costs, set up transportation services at each clinic to shuttle patients)
- Let go of cultural traditions that perpetuate spread of HIV such as the national maganu (amarula) ceremony, subjugation and subordination of women, and polygamy/multiple concurrent sex partners.
- Design and implement strategies to reduce alcohol consumption in the county, such as restricting alcohol consumption in public, increasing awareness about the effects of alcohol on health, legally required health warning labels on alcohol advertisements / containers, and increasing access to psychotherapy and alcohol rehabilitation programs.

CHAPTER 8

SUMMARY AND CONCLUSIONS

A growing body of evidence indicates that factors across multiple levels interact and influence ART adherence. Interpersonal, social and structural barriers as well as individual-level behaviors have been shown to affect access to and use of HIV treatment. While HIV/AIDS intervention strategies have been implemented by the government of Eswatini and by private organizations to help fight against HIV/AIDS for decades, lack of compliance with treatment continues to remain a significant challenge for HIV/AIDS programs throughout the country. For HIV/AIDS programs to be successful in ensuring treatment adherence and patients' retention to care, it is critical to investigate and identify factors that may facilitate or inhibit access and utilization of treatment.

Health behaviors are better understood with the use of a theoretical framework that takes into consideration complex ecological dynamics and their interaction with individual factors. Employing a SEM, we conducted a mixed methods study to investigate barriers to ART adherence, with a specific focus on clarifying the critical associations between household food insecurity and proximity to a healthcare facility on ART adherence. The SEM model used in our study helped us understand the manner in which factors within multiple levels exert an influence on individual health behaviors. While other HIV studies have investigated factors which facilitate or hinder optimal HIV treatment, *this study is unique in its use of the SEM and mixed methods design to investigate the factors that influence ART adherence among women in rural Eswatini*. Our study is also distinctive given that few studies locally/regionally have utilized the SEM and a mixed methods design to investigate influences of ART adherence beyond the individual level. This study addresses ART adherence in a comprehensive manner and provides important information to help enhance understanding of complex behavioral influences of ART adherence in the country with the highest HIV prevalence in the world. Additionally, previous

studies investigated these barriers in urban settings, while our study focuses on rural women. *To our knowledge, our study is the only one to reveal additional barriers such as gossip and alcohol use by healthcare workers that had not been reported in previous studies.*

Our findings indicate that the majority (56%) of the women in our study were nonadherent to ART. At the individual level, factors identified by study participants as barriers to ART adherence included: hunger, hunger-related medication side effects, stress, stigma (both self-stigma and perceived public-stigma), forgetting or being too busy to take pills, being unsure of time to take medication, pill bottles rattle too loudly, and pills too big to swallow. Excessive alcohol use was identified by healthcare workers as a negative influence on ART adherence. Lack of food at home, low socioeconomic status, and lack of disclosure/accidental disclosure were identified by women as barriers to ART adherence at the household level. Healthcare workers reported the same issues as in the group discussions, but thought patients' belief in traditional medicine and tolerance of polygamous relationships were additional negative influences on ART adherence. Community/institutional level barriers included: lack of privacy at the clinic, travel time and transportation costs, gossip in the community, maltreatment by health workers, and excessively long waits at clinics. Some unexpected but commonly reported barriers by study participants included local employers not allowing workers to take time off for clinic visits, and healthcare workers reporting excessive alcohol use among co-workers while on duty.

Of the barriers identified from qualitative findings, nine (hunger, hunger-related medication side effects, feelings of stress, forgetfulness, mode of transport, age, gossip, maltreatment by clinic staff, and community support) were found to be significantly associated with ART adherence from quantitative results. Hunger and hunger-related medication side effects were reported by all most all women as the main reason women skipped taking medication. The mechanisms through which food insecurity influenced adherence within our study population were: 1) concern over lack of food/ food supply within the household, 2) avoidance of medication/delaying ART when households had insufficient food,

and 3) skipping doses entirely when women had no prospects of procuring food. This was particularly challenging for women living in poverty who often reported going several days without enough food to eat. In our study and others in the region, household food insecurity has been identified as a significant barrier to ART adherence. Providing food supplements and nutritional support has been shown to improve ART adherence. It stands to reason that future strategies aimed at improving ART adherence and alleviating the AIDS crisis in Eswatini should include programs which provide supplemental food and nutrition support for people living with HIV.

Our qualitative analysis revealed that transportation costs were a major barrier to ART adherence, however this association was not significant in quantitative analysis. In contrast, mode of transport was found to be a significant predictor of ART adherence. For rural Swazis, it is uncommon to own a car, and most of our study participants reported having to walk or take a kombi (mini-bus) to the clinic for monthly medication pick-up or appointments. For most of the participants, traveling long distances to receive treatment was common, with transportation difficulties reported by both the women and healthcare workers as contributing factors to nonadherence. In focus group discussions, women reported having to walk to clinics when they lacked sufficient funds to pay for transport. For women living in particularly remote areas, walking to the nearest clinic could take several hours, and was especially difficult on days with extreme weather. Similar findings were reported by other studies in the region, where individuals reported extensive walk times (particularly when traveling in harsh weather conditions) as the main reason they missed clinic visits. While Comm ART services have the potential to improve ART adherence, issues of stigma and gossip which are rampant in these communities may inhibit success of these programs. Increasing interventions aimed at addressing stigma by raising awareness and acceptance of those living with HIV may reduce patient anxiety toward accessing local ART services in rural communities. In order to encourage the utilization of local ART

services and reduce treatment default, it is essential to intensify strategies at both national and local (chiefdom) levels to eradicate all forms of HIV stigma among rural populations.

Poor treatment of participants by clinic staff was reported by most women to be a major barrier to ART and was found to be significantly associated with ART nonadherence. In group discussions, participants who were either late to or missed appointments often encountered unpleasant experiences with clinic staff, including disparagement, punitive punishment, getting yelled at, and general rude behavior. Lack of professionalism and maltreatment by healthcare workers has been associated with poor health care attendance and has been shown to negatively impact ART adherence. Initiatives are needed to retrain healthcare workers regarding professional conduct, sensitivity towards patients' needs, and confidentiality of patients' medical records.

The poorest and most vulnerable HIV patients in Eswatini face daily challenges that significantly impact ART adherence. Women living in rural communities at high risk of poor HIV care and management would benefit significantly from programs designed to reduce poverty and unemployment, easing their financial burden regarding HIV treatment. Programs utilizing new strategies to improve ART adherence (reducing stigma, food programs in conjunction with ART treatment, greater focus on outreach programs in remote areas, and re-training health care workers) must be prioritized for Eswatini to achieve its goal of eradicating new infections and ending AIDS by 2022.

APPENDIX A

DEMOGRAPHIC CHARACTERISTICS OF STUDY PARTICIPANTS

Characteristic	N	Percentage	Mean (SD)
Age	166		37 (7.3)
Travel time	149		1.9 hours (1.7)
Educational level			
No school	39	23.5	
Primary	82	49.4	
Secondary/High	45	27.1	
Adherence status			
No	93	56.0	
Yes	73	44.0	
Marital Status			
Married/ living with partner	94	56.6	
Not married	72	43.4	
Relationship status			
Monogamous	73	45.9	
Polygamous	25	15.7	
Committed	61	38.4	
Lives with husband/ partner			
No	98	61.3	
Yes	62	38.7	
Employment Status			
Not employed	91	54.8	
Employed full-time	20	12.1	
Employed part-time	20	12.1	
Employed seasonally	11	6.6	
Self-employed	24	14.4	
Income			
<=500	91	55.1	
500+	74	44.9	
Transport mode			
Walking	110	66.3	
Vehicle	56	33.7	
Refill			
Local clinic	150	90.4	
Other	16	9.6	

Alcohol use		
None drinkers	130	78.8
Drinkers	35	21.2
Adherence status		
Adherent	73	44.0
Nonadherent	93	56.0
Had sex		
No	68	59.0
Yes	98	41.0
Condom use		
Always	43	44.8
Sometimes	37	38.5
Never	16	16.7
Husband/partner on ART		
No	30	18.2
Yes	135	81.8
Health status		
Good	116	69.9
Poor	50	30.1
Household food insecurity		
Food secure	2	1.2
Mildly food insecure	12	7.2
Moderately food insecure	46	27.7
Severely food insecure	106	63.9
Hunger		
No	45	27.3
Yes	120	72.7
Side effects_general		
No	153	94.4
Yes	9	5.6
Side effects_no food		
No	49	29.5
Yes	117	70.5
Too far		
No	144	86.8
Yes	22	13.2
No money		
No	140	84.3
Yes	26	15.7
Pills too loud		
No	159	95.8
Yes	7	4.2

Forgetfulness		
No	129	77.7
Yes	37	22.3
Stress		
No	124	74.7
Yes	42	25.3
Poor treatment		
No	137	82.5
Yes	29	17.5
Longlines		
No	160	96.4
Yes	6	3.4
Too many pills		
No	153	92.2
Yes	13	7.8
Experience Stigma		
No	140	85.9
Yes	23	14.1
Gossiped about		
No	102	63.0
Yes	60	37.0
Avoided		
No	128	78.5
Yes	35	21.5
Family support		
No	80	48.8
Yes	84	51.2
Community support		
No	146	89.6
Yes	17	10.4

APPENDIX B

MEASURES OF ASSOCIATION BETWEEN EXPOSURE VARIABLES AND ART ADHERENCE

	Adherent		Non-adherent		P-value
Characteristics	N	%	N	%	
Age	73	44.0	93	56.0	0.000
Travel time	63	42.3	86	59.7	0.188
Transportation costs	73	44.2	92	55.8	0.699
Educational level					0.307
No school	21	53.9	18	46.2	
Primary	32	39.0	50	61.0	
Secondary/High	20	44.4	25	55.6	
Marital Status					0.461
Married/ living with partner	39	41.5	55	58.5	
Not married	34	47.2	38	52.8	
Marriage type					0.016
Monogamous	30	41.1	43	58.9	
Polygamous	17	68.0	8	32.0	
Committed	21	34.4	40	65.6	
Lives with husband/ partner					0.588
No	40	40.8	58	59.2	
Yes	28	45.2	34	54.8	
Employment Status					0.758
Not employed	41	45.1	50	55.0	
Employed	32	42.7	43	57.3	
Income					0.691
<=500	39	42.9	52	57.1	
500+	34	46.0	40	54.1	
Transport mode					0.076
Walking	43	39.1	67	60.9	
Vehicle	30	53.6	26	46.4	
Prescription refill					0.036

Local clinic	62	41.3	88	58.7	
Other	11	68.8	5	31.3	
Alcohol use					0.101
None drinkers	61	46.9	69	53.1	
Drinkers	11	15.3	24	68.6	
Had sex in past month					0.001
No	40	58.8	28	41.2	
Yes	33	33.7	65	66.3	
Household food insecurity					0.331
Food secure	1	50.0	1	50.0	
Mildly food insecure	6	50.0	6	50.0	
Moderately food insecure	25	54.4	21	45.7	
Severely food insecure	41	38.7	65	61.3	
Hunger					0.000
No	30	66.7	15	33.3	
Yes	43	35.8	77	64.2	
Side effects_general					0.514
No	68	44.4	85	55.6	
Yes	3	33.3	6	56.2	
Side effects_no food					0.000
No	37	75.1	12	24.5	
Yes	36	30.8	81	69.2	
Clinic too far					0.009
No	69	47.9	75	52.1	
Yes	4	18.2	18	81.8	
No money					0.019
No	67	47.9	73	52.1	
Yes	6	23.1	20	76.9	
Pills too loud					0.106
No	72	45.3	87	54.7	
Yes	1	14.3	6	85.7	
Forgetfulness					0.006
No	64	49.6	65	50.4	
Yes	9	24.3	28	75.7	
Stress					0.001
No	64	51.6	60	48.4	
Yes	9	21.4	33	78.6	
Poor treatment					0.005
No	67	48.9	70	51.1	
Yes	6	20.7	23	79.3	

Long lines					0.170
No	72	45.0	88	55.0	
Yes	1	16.7	5	83.3	
Too many pills					0.006
No	72	47.1	81	52.9	
Yes	1	7.7	12	92.3	
Experience Stigma					0.078
No	64	45.7	76	54.3	
Yes	6	26.1	17	73.9	
Gossiped about					0.013
No	51	50.0	51	50.0	
Yes	18	30.0	42	70.0	
Avoided					0.434
No	57	44.5	71	55.5	
Yes	13	37.1	22	62.9	
Family support					0.289
No	38	47.5	42	52.5	
Yes	33	39.3	51	60.7	
Community support					0.162
No	60	41.1	86	58.9	
Yes	70	42.9	93	57.0	

APPENDIX C

INTERVIEWER GUIDE FOR KEY INFORMANTS

Guide for Key Informants Interview

University of Massachusetts, Amherst

Study: Association of Household Food Insecurity with HAART Adherence Among HIV-infected Women in Swaziland: a Mixed Methods Approach

Introduction

Thank you for taking time out of your busy schedule to meet with me today. My name is _____, I am part of the research team from the UMass, Amherst study. As you may know, we are working on a project to investigate barriers to HIV medication adherence among women. We would like to talk to members of your organization who might be able to provide us with some insight regarding intrapersonal, social, and structural factors that the women you serve report as barriers to HIV treatment. We know that adherence to HIV medications is important to the long-term success of comprehensive HIV care, but we also know that there are many challenges women face in taking these medications. We want to learn what you have observed regarding these challenges for women in this community.

We will take what you say to help inform policies to improve the effectiveness of support programs aimed at increasing HAART adherence among women in Swaziland

We will be making an audio recording of our discussion so that we can remember exactly what you said. But please remember that everything we discuss is confidential. We will take all the information given to us and put it together. No one will be identified nor will any names be recorded in the information we collect for the project.

This interview should take no more than 60 minutes.

Before we begin, I want to go over the consent form with you and answer any questions you may have about the study.

Once the consent form is signed, start the audio recording and begin the interview.

Tell me about the women in your community? (Probe for: demographics, atmosphere, what you feel proud about, what are some challenges?)

What is the nature of your usual interaction with the women you serve?

What are some of the issues you see among women on HAART?

What is your sense about the women's attitude/feelings towards HAART? How about their spouses/friends/family members?

What kind of comments or stories do you hear from the women about HAART in general?

What are some of the reasons women give for not taking their medication consistently?

Do you think cultural traditions/societal norms (e.g. polygamy) play a role in whether or not women take HAART? If so, how?

Do you think women generally receive support from their community or family members who are aware of their HIV status? In what ways?

Do people generally treat those taking ARVs badly in your community? Or speak poorly/gossip about them?

Please describe any issues regarding stigma with ARVs in your community.

Are there programs designed to help support people taking ARVs in your community? What kind of support do these programs give?

What strategies do you use to track people who are defaulting on treatment?

In your opinion, what kind of policies/interventions should be implemented to help resolve the structural and social barriers to HAART adherence?

APPENDIX D

MODERATOR GUIDE FOR FGDS

Moderator's Guide for Focus Group Discussion

Study: Association of Household Food Insecurity with HAART Adherence Among HIV-infected Women in Swaziland: a Mixed Methods Approach

Introduction

Moderator and observer greet the group and introduce themselves. Start handing out the consent forms.

Go over the form with participants. Next, explain that all participants must read the consent form being passed out, and sign the form if they agree to be part of the study. Time is given for participants to complete the form before beginning the session.

While collecting, check that all of the consent forms are properly signed. Participants will then be asked to provide some demographic data (moderator and observer administer demographic questionnaires individually with each participant)

Begin group discussion.

Please help yourself to the snacks we brought for you. This will be a very informal discussion so make yourselves comfortable.

Moderator:

We want to begin by thanking you for taking the time out of your day to share your thoughts and experiences with us. We really appreciate you helping us with this work. As you may have read or heard, we are working on understanding barriers to HIV medication adherence. Recent reports from the ministry of health have shown that many people have difficulties adhering to their HIV medication and we are trying to understand why by working with you to identify the problems that women encounter regarding treatment. We are holding these focus groups with women who have had similar experiences to come together and talk. We are interested in gaining an in-depth understanding of the intrapersonal (women's attitudes, experiences, and feelings towards HAART), social, and structural barriers associated with HAART adherence. This focus group is not about being judgmental toward each other's experiences, and we hope everyone here can be understanding and supportive of each other while we discuss this very sensitive and personally challenging issue. We really are more interested in you being honest and sharing your everyday experiences. We think we can learn much from hearing firsthand about the realities of HAART adherence. We want to hear about the challenges you face with adherence, and when you are adherent to medication, what helps you to stay that way.

We will study your responses with the goal of developing effective treatment support programs to resolve structural and social barriers to HAART adherence among women in rural areas.

We will be voice recording our discussion so that we can remember exactly what is said; additionally we have someone here who is writing down what we talk about. But please remember that we will not be identifying anyone by name in our work. We take all the information given to us and put it all together anonymously. All of your answers will be completely confidential, and your name will never be given to anyone. The discussion will be recorded but your name will not be connected to the information gathered.

As you talk to us about your experiences, let's make sure we all remember to respect each other and let the person talking finish what they are saying, before you add your piece. Also remember there are no wrong or right answers, we just want to know your experiences and what you think.

Moderator: Before we get started we need to establish a few group rules. These rules help to guide our discussion, so that everyone feels like this is a safe place to say what they feel. Remember there are no right answers, just people's opinions and experiences. It is important to respect each person's opinion, you do not have to agree but we have to respect what each person has to say. The group rules are as follows:

- a) One person speaks at a time.
- b) Everyone is entitled to their opinion.
- c) Do not tell anyone else what was discussed in the group.
- d) Please put your phones away and keep them on silent for the duration of the discussion.

Are there any other rules you think we should add?

We would like to repeat that we are interested in what you really think, so if you disagree what is being said that is perfectly fine- give us your opinion.

The focus group should last about one and a half hours, please help yourself to more snacks as we go along.

Let's get started.

Moderator turns the audio recorder on, observer begins to take notes.

Focus Group Questions:

1. Tell us your feelings about/experiences with ARVs? What do you like/dislike about the medication? What challenge do you face regarding taking ARVs?

2. Are there any activities/responsibilities in your daily life that makes it difficult for you to take your ARVs? If yes, what are they? Please describe/list them.
3. We want to know about the kind of support you get from friends and relatives. Do you feel you have support? If not, how does that make you feel? If so, who helps you and in what way do they help?
4. Do you have family, friends and/or places in your neighborhood (like your church or community center) that you find helpful for any of your needs? If so tell us about all the type of help/support you get?
5. What do ARVs mean to you, what do you think of them?
6. When did you start taking ARVs, how do you feel about taking them?
7. Does your spouse/partner/anyone in your family take ARVs?
8. Did you tell your spouse/partner/anyone in your family that you are taking ARVs? If so, who? If not, why not?
9. What would happen if your spouse/partner/family did not support you because of taking ARVs- who's opinion in the family or in your life would be the most important for you to listen to?
10. How do your family and friends feel about you taking ARVs?
11. Do you feel the community supports you as a person living with HIV? If so, how? If not, how would you like the community to support you?
12. Are there programs designed to help support people taking ARVs in your community? What kind of support do these programs give?
13. Tell us about problems you encounter with taking ARVs. How do you solve them?
14. Tell us about your hospital/clinic experience during your visits. Any problems? Do you feel supported by the clinic staff? Does the doctor/nurse answers any questions or concerns you might have about the treatment?

Moderator: Now we want to switch gears a little and have you tell us your ideas and suggestions for what kind of support you think would be helpful to help women adhere to medication. The support may be different according to the place/setting. For example: what kind of support would a woman need at home/in the community that would help her take medication constantly?

Working in pairs we would like you to tell us the types of changes you would like to see in: 1) the home; 2) in the clinic/ hospital; 3) in the community; 4) in your church.

Write your ideas and suggestions on this paper (hand paper out).

[The moderator will provide 10-15 minutes for pairs to discuss their responses. The moderator will circulate to answer questions/clarify etc.]

Note: not every pair will have suggestions for each type of supports within each setting. That's fine, we are only interested in what topics the question elicits.

Moderator: *Let's take a few moments to hear from each pair.*

Moderator: *now on your own we would like you to complete the following statements. You do not have to write your name on the paper [moderator hands out paper with these 6 topics]:*

What helped me decide to take ARVs?: _____

What makes me miss taking my ARVs?: _____

What I like the most about being on treatment?: _____

What is the hardest about being on ARVs?: _____

What I would like to see happen with my health?: _____

What I need to do to adhere to my ARVs?: _____

Finally: is there anything else you want to share with us? Any ideas, observations, or suggestions that we have not covered today but you have previously thought about?

We want to thank you for your time and for sharing with us your experiences, ideas and opinions. When we have finished our study, we would be happy to share with you what we heard from you as a group (not individually). Please let us know if you are interested and we will get in touch with you when we get everyone together to hear the results.

APPENDIX E

SURVEY QUESTIONNAIRE

Survey Questionnaire

PTID					Enrollment Date		
==	=====	=====	==	=====	DD	MM	YY
Enumerator: _____					Supervisor: _____		

Instructions: Use this Routine Questionnaire for all participants meeting the eligibility criteria who have provided written informed consent to participate. Please do not leave any questions blank. Instead, mark the “DK” box if the participant states that they “don’t know” the answer to a question. If the participant is willing to answer but doesn't know the exact answer, encourage her to estimate, as this is better than a DK answer. If the participant refuses to answer a question, mark the “REF” box for “refused” to answer.

Demographics

Interviewer reads:

Thank you for participating in our study. First, I would like to ask you a few questions. Some of these questions may be uncomfortable to answer. Please answer honestly, not what you think we want to hear, there is no right or wrong answer. You will not be judged or criticized based on any of the answers you provide. If I ask a question that you don’t want to answer, just let me know and I will go on to the next question. Please remember that you do not have to answer any questions that you do not want to answer and you may discontinue the interview at any time. But remember, nothing you say here will ever be repeated to anyone else, and no one will ever use your name. Also, the information you give by answering these questions might help others in the future and may lead to some changes which could reduce the problem of AIDS here in Swaziland. Our discussion should last less than one hour.

1. Where do you live? _____
2. Were you living in this community during your last clinic visit?
☐ Yes
☐ No
☐ Other, please specify _____

- ☐ DK
- ☐ REF

3. How many people are currently living in your household? _____
4. How many are children? _____ *number of children (below 18)*
5. How many are adults (including yourself)? _____ *number of adults (18 or older)*

6. What is the highest degree or level of school you have completed?

- ☐ Did not attend school
- ☐ Primary
- ☐ Secondary/High
- ☐ College/University
- ☐ DK/REF

Question 7 Instructions: Read choices out loud to participant. Mark the one best answer.

7. I would like to ask you about your employment status. Are you currently....?

- ☐ Employed full time
- ☐ Employed part-time
- ☐ Employed seasonally
- ☐ Self-employed
- ☐ Stay at home mom
- ☐ Student
- ☐ Retired or disabled
- ☐ DK
- ☐ REF

8. Is your approximate monthly household income from all sources...

- ☐ Less than E500
- ☐ E500 – E1000
- ☐ E1001 – E2000
- ☐ E2001 – E5000
- ☐ E5001 – E10000
- ☐ E10000 or more
- ☐ DK
- ☐ REF

9. At present are you.....?

- ☐ Never married
- ☐ Married
- ☐ Living with your partner
- ☐ Separated, but still legally married
- ☐ Divorced
- ☐ Widowed

- ☐ DK
- ☐ REF

10. Are/Were you in a.....?

- ☐ Polygamous marriage
- ☐ Monogamous marriage
- ☐ Committed relationship with one sex partner
- ☐ Open relationship with multiple sex partners
- ☐ DK
- ☐ REF

11. Is your husband or partner living with you now or are they staying elsewhere?

- ☐ Living with me
- ☐ Staying elsewhere
- ☐ DK
- ☐ REF

12. Are you currently pregnant?

- ☐ Yes
- ☐ No
- ☐ DK
- ☐ REF

13. Over the past 12 months, would you say that your health has been generally...

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ DK
- ☐ REF

14. Do you have any health problem that requires medical attention, such as hypertension, diabetes, heart disease, etc?

- ☐ Yes
- ☐ No
- ☐ DK
- ☐ REF

If yes, please specify_____

If you are taking medications for your condition(s), what are they?

15. Have you used alcohol in the past 12 months?

- ☐ Yes
- ☐ No (skip to Q18)
- ☐ DK
- ☐ REF

16. During the past 30 days, how many days per week did you have at least one drink of any alcohol beverage such as beer, wine, a malt beverage or liquor?

_____ number of days

- DK
- REF

17. One drink is equivalent to a 330ml beer (normal size beer can), a 150ml glass of wine (half a glass full), or a drink with one shot of liquor. During the past 30 days, on the days when you drank, about how many drinks did you drink on average?

_____ number of drinks

- DK
- REF

18. In the past four weeks, have you worried that your household would not have enough food?

- ☐ No (**skip to Q19**)
- ☐ Yes

If YES, how often did this happen?

- ☐ Rarely
- ☐ Sometimes
- ☐ Often

19. In the past four weeks, were you or any household member not able to eat the kinds of foods you preferred because of lack of resources?

- ☐ No (**skip to Q20**)
- ☐ Yes

If YES, how often did this happen?

- ☐ Rarely
- ☐ Sometimes
- ☐ Often

20. In the past four weeks, did you or any household member have to eat a limited variety of foods due to lack of resources?

- ☐ No (**skip to Q21**)

☐ Yes

If YES, how often did this happen?

- ☐ Rarely
- ☐ Sometimes
- ☐ Often

21. In the past four weeks, did you or any household member have to eat some foods that you really did not want to eat because of lack of resources to obtain other types of food?

☐ No **(skip to Q22)**

☐ Yes

If YES, how often did this happen?

- ☐ Rarely
- ☐ Sometimes
- ☐ Often

22. In the past four weeks, did you or any household member have to eat a smaller meal than you felt you needed because there was not enough food?

☐ No **(skip to Q23)**

☐ Yes

If YES, how often did this happen?

- ☐ Rarely
- ☐ Sometimes
- ☐ Often

23. In the past four weeks, did you or any household member have to eat fewer meals in a day because there was not enough food?

☐ No **(skip to Q24)**

☐ Yes

If YES, how often did this happen?

- ☐ Rarely
- ☐ Sometimes
- ☐ Often

24. In the past four weeks, was there ever no food to eat of any kind in your household because of lack of resources to get food?

☐ No **(skip to Q25)**

☐ Yes

If YES, how often did this happen?

- ☐ Rarely
- ☐ Sometimes
- ☐ Often

25. In the past four weeks, did you or any household member go to sleep at night hungry because there was not enough food?

☐ No (**skip to Q26**)

☐ Yes

If YES, how often did this happen?

☐ Rarely

☐ Sometimes

☐ Often

26. In the past four weeks, did you or any household member go a whole day and night without eating anything because there was not enough food?

☐ No

☐ Yes

If YES, how often did this happen?

☐ Rarely

☐ Sometimes

☐ Often

SEXUAL ACTIVITY

Instructions: This section of the form addresses sexual behaviors and asks that the participant recall his/her sexual partners over the past 12 months.

Interviewer reads:

Now I would like to ask you some questions about your recent sexual activity. I know these questions are sensitive and want to remind you that your answers are completely private. This means that they will not be shared with anyone outside of the study team. No one will know what particular answers you give. This form will not have your name anywhere on it. Instead, you will only be identified by a number. If we should come to any questions that you don't want to answer, just let me know and we will go on to the next one.

Different people have different definitions of "sex" or "sexual intercourse." For this study, when we say "sex" we mean:

- Vaginal sex, which is when a man puts his penis in a woman's vagina.
- Anal sex, which is when a man puts his penis in another person's anus.

Do you have any questions before continuing?

27. How old were you when you had sexual intercourse for the very first time?

☐ Age (Years) _____

☐ Have never had sex

☐ DK

☐ REF

If have never had sex, skip to HIV Status section.

28. In total, with how many different people have you had sexual intercourse in the last 12 months? It is okay to estimate the number if you do not remember exactly.

- ☐ Number of partners_____
- ☐ Zero
- ☐ DK
- ☐ REF

If zero, skip to HIV Status section.

29. With the ***(insert number of partners from question 28 or say “this or these” if 28 = REF)*** sex partners that you have had in the last 6 months, how often did you use a condom when you had sexual intercourse?

- ☐ Always
- ☐ Sometimes
- ☐ Never
- ☐ DK
- ☐ REF

30. Did you engage in sexual intercourse with this person (s) in exchange for money or food?

- ☐ Yes
- ☐ No **(skip to next section: “HAART Information”)**
- ☐ DK
- ☐ REF

31. How often did you receive (or give) money or gifts so that you could have sex with this person/people?

- ☐ Always
- ☐ Sometimes
- ☐ Never
- ☐ DK
- ☐ REF

32. When you were having a sexual relationship with this partner (s), do you think that he/she was HIV positive?

- ☐ Yes
- ☐ No
- ☐ DK
- ☐ REF

33. Do you think that this partner was taking ARVs for HIV/AIDS?

- ☐ Yes
- ☐ No
- ☐ DK
- ☐ REF

HAART INFORMATION

Instructions: This section of the form addresses access to HAART and HAART Adherence.

Interviewer reads:

Now I would like to ask you some questions about your ARVs. First I would like to take a look at your medical card and your ARVs. I need to record some information from your card and count the number of pills you have left for this cycle. I will then ask you questions about how often you take your ARVs. Your medical information and answers to the questions are completely private. This form will not have your name anywhere on it; instead you will only be identified by a number.

34. Mark participant's height and weight.

Height_____ Weight_____

35. Mark age (date of birth).

Year_____ If unknown, ask current age. Estimate OK. Age_____

36. Record the number of last CD4 cell count.

Cell count_____

37. Record the date of last clinic visit and scheduled visit.

Last clinic visit_____ Scheduled visit_____

38. Count and record the number of pills in possession.

Number of pills_____

39. How often do you feel that you have difficulty taking your HIV medications on time? By 'on time' we mean no more than two hours before or two hours after the time your doctor told you to take it.

- ☐ Never
- ☐ Rarely
- ☐ Most of the time
- ☐ All of the time

40. On average, how many days per week would you say that you missed at least one dose of your HIV medications?

- ☐ Everyday
- ☐ 4-6 days/week
- ☐ 2-3 days/week
- ☐ Once a week
- ☐ Less than once a week
- ☐ Never

41. When was the last time you missed at least one dose of your HIV medications?

- ☐ Within the past week
- ☐ 1–2 weeks ago
- ☐ 3–4 weeks ago
- ☐ Between 1 and 3 months ago
- ☐ More than 3 months ago
- ☐ Never

42. How important are ARVs to you as a person living with HIV? Would you say...

- ☐ Very important
- ☐ Somewhat important
- ☐ Not very important
- ☐ DK
- ☐ REF

43. In the past month have you experienced any side effects from your ARVs?

- ☐ Yes
- ☐ No (**skip to Q45**)
- ☐ DK
- ☐ REF

44. What kind of side effects have you experienced?

- ☐ Increased appetite
- ☐ Nausea
- ☐ Vomiting
- ☐ Dizziness
- ☐ Diarrhea
- ☐ Rash in the mouth
- ☐ Other, please specify_____

45. What year and month did you start taking ARVs? (if unsure, get best estimate possible)

Year_____ Month_____

46. Does your spouse/partner/anyone in your family take ARVs?

- ☐ Yes
- ☐ No
- ☐ DK
- ☐ REF

47. Did you tell your spouse/partner/anyone in your family that you are taking ARVs?

- ☐ Yes
- ☐ No
- ☐ DK
- ☐ REF

If so, who? _____

48. Do you feel the community supports you as a person living with HIV? If so, how?

- ☐ Yes
- ☐ No
- ☐ REF

If YES, please describe_____

49. Do you feel stigmatized by friends and family members due to taking ARVs?

- ☐ Yes
- ☐ No
- ☐ DK
- ☐ REF

50. In the last 12 months, how often have felt like you have been gossiped about because of your ARVs and HIV status?

- ☐ Always
- ☐ Sometimes
- ☐ Never
- ☐ DK
- ☐ REF

51. Have you been avoided by friends/family members because you are taking ARVs?

- ☐ Always
- ☐ Sometimes
- ☐ Never
- ☐ DK
- ☐ REF

52. We want to know about the kind of support you get from friends and relatives. Do you feel you have support?

- ☐ Yes
- ☐ No
- ☐ DK
- ☐ REF

If so who helps you and in what way do they help?_____

53. Do you have family, friends and/or places in your neighborhood- like your church or a community center that you find helpful for some of your needs?

- ☐ Yes
- ☐ No
- ☐ DK
- ☐ REF

If YES, tell us about all the type of help/support you get?

54. Is there a clinic/hospital in your community?

- ☐ Yes
- ☐ No (skip to Q56)
- ☐ DK
- ☐ REF

55. Does the clinic/hospital provide ARVs and refills?

- ☐ Yes
- ☐ No
- ☐ DK
- ☐ REF

56. Where do you get your ARV refills?

- ☐ Local clinic/hospital
- ☐ Other, please specify_____

If other, why?_____

57. What mode of transport do you take to get to the clinic?

- ☐ Walking
- ☐ Public transportation
- ☐ Other, please specify_____

If public transport, how much do you spend on transportation costs?

E_____

58. On average, how much time does it take you to get to the clinic/hospital?

Hours_____ Minutes_____

This concludes the questionnaire. We really appreciate the time and effort you've spent answering these questions. Thank you so much for participating!

59. Mark exact location of participants' residence on map. Using GPS/Google Maps, estimate travel distance (kilometers) from participants home to clinic/hospital.

Walking _____

Vehicle _____

APPENDIX F

CASE ADHERENCE QUESTIONNAIRE

Case Adherence Index questionnaire

A1. How often do you feel that you have difficulty taking your HIV medications on time? By 'on time' we mean no more than two hours before or two hours after the time your doctor told you to take it.

- [4] Never
- [3] Rarely
- [2] Most of the time
- [1] All of the time

A2. On average, how many days per week would you say that you missed at least one dose of your HIV medications?

- [1] Everyday
- [2] 4–6 days/week
- [3] 2–3 days/week
- [4] Once a week
- [5] Less than once a week
- [6] Never

A3. When was the last time you missed at least one dose of you HIV medications?

- [1] Within the past week
- [2] 1–2 weeks ago
- [3] 3–4 weeks ago
- [4] Between 1 and 3 months ago
- [5] More than 3 months ago
- [6] Never

INDEX SCORE: _____

>10 = good adherence

≤10 = poor adherence

APPENDIX G

INSTITUTIONAL REVIEW BOARD



University of Massachusetts Amherst
108 Research Administration Bldg.
70 Butterfield Terrace
Amherst, MA 01003-9242

Research Compliance
Human Research Protection Office (HRPO)
Telephone: (413) 545-3428
FAX: (413) 577-1728

Certification of Human Subjects Approval

Date: June 28, 2017
To: Nozipho Maziya, Nutrition
Other Investigator: Lindiwe Sibeko, Nutrition
From: Lynnette Leidy Sievert, Chair, UMASS IRB

Protocol Title:(FULL BOARD) Association of Household Food Insecurity with HAART Adherence Among HIV-infected Women in Swaziland; a Mixed Methods Approach
Protocol ID: 2016-3309
Review Type:EXPEDITED - REVISION
Paragraph ID: 7
Approval Date: 06/28/2017
Expiration Date:02/05/2018
OGCA #:

This study has been reviewed and approved by the University of Massachusetts Amherst IRB, Federal Wide Assurance # 00003909. Approval is granted with the understanding that investigator(s) are responsible for:

Modifications - All changes to the study (e.g. protocol, recruitment materials, consent form, additional key personnel), must be submitted for approval in e-protocol before instituting the changes. New personnel must have completed CITI training.

Consent forms - A copy of the approved, validated, consent form (with the IRB stamp) must be used to consent each subject. Investigators must retain copies of signed consent documents for six (6) years after close of the grant, or three (3) years if unfunded.

Adverse Event Reporting - Adverse events occurring in the course of the protocol must be reported in e-protocol as soon as possible, but no later than five (5) working days.

Continuing Review - Studies that received Full Board or Expedited approval must be reviewed three weeks prior to expiration, or six weeks for Full Board. Renewal Reports are submitted through e-protocol.

Completion Reports - Notify the IRB when your study is complete by submitting a Final Report Form in e-protocol.

Consent form (when applicable) will be stamped and sent in a separate e-mail. Use only IRB approved copies of the consent forms, questionnaires, letters, advertisements etc. in your research.

Please contact the Human Research Protection Office if you have any further questions. Best wishes for a successful project.



Research Protocol clearance certificate

Type of review	Expedited	<input checked="" type="checkbox"/>		Full Board	<input type="checkbox"/>
Name of Organization	STUDENT				
Title of study	ASSOCIATION OF HOUSEHOLD FOOD INSECURITY WITH HART ADHERENCE AMONG HIV INFECTED WOMEN IN SWAZILAND: A MIXED METHOD APPROACH				
Protocol version	1.0				
Nature of protocol	New	<input checked="" type="checkbox"/>	Amendment	<input type="checkbox"/>	
List of study sites	MATSANJENI, GOOD SHEPERD, ST. PHILLIPS AND SIPHOFANENI				
Name of Principal Investigator	NOZIPHO MAZIYA				
Names of Co- investigators	N/A				
Names of steering committee members in the case of clinical trials	N/A				
Names of Data and Safety Committee members in the case of clinical trials	N/A				
Level of risk (Tick appropriate box)	Minimal	<input checked="" type="checkbox"/>	High	<input type="checkbox"/>	
Clearance status (Tick appropriate box)	Approved	<input checked="" type="checkbox"/>	Disapproved	<input type="checkbox"/>	
Clearance validity period	Start date	21/04/2017	End	21/04/2018	
Signature of Chairperson	 				
Date of signing	21/04/2017				
Secretariat Contact Details	Name of contact officers	Ms. Mphahlele Mphahlele			
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